Bioresponse System

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BIORESPONSE SYSTEM

Supporting professional caregivers of clients with visual and severe/profound intellectual disabilities

Kyra Frederiks

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Supporting professional caregivers of clients with visual and severe/profound intellectual disabilities

PROEFSCHRIFT

ter verkrijging van de graad van doctor aan de Technische Universiteit Eindhoven, op gezag van de rector magnificus prof.dr.ir. F.P.T. Baaijens, voor een commissie aangewezen door het College voor Promoties, in het openbaar te verdedigen op vrijdag 10 december 2021 om 11:00 uur

door

Kyra Frederiks
geboren te Geleen

Dit proefschrift is goedgekeurd door de promotoren en de samenstelling van de promotiecommissie is als volgt:

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Het onderzoek of ontwerp dat in dit proefschrift wordt beschreven is uitgevoerd in overeenstemming met de TU/e Gedragscode Wetenschapsbeoefening.

Summary

People with visual and severe or profound intellectual disabilities (V-S/PID) depend on their (professional) caregivers for daily care and socialization. Successful socialization is contingent on four key components: sensitive responsiveness, joint attention, emotions, and co-regulation (a collective term for attunement, reciprocity, mutuality, and turn-taking). However, the subtle and often non-verbal communicative behavior of people with V-S/PID can be complex to understand for their caregivers. The quality of the interaction between caregivers and people with V-S/PID may be jeopardized due to this subtle communicative behavior.

Another consequence of this subtle communicative behavior is that it may lead to the misunderstanding or ignorance of the needs and wishes of people with V-S/PID. Being misunderstood leads to stress. Stress and communication impairments are major causes for the occurrence of challenging behavior. Challenging behavior is behavior of such intensity, duration, or frequency that the quality of life, the personal physical safety of the individual, and the physical safety of others are at risk. Individuals with V-S/PID show challenging behavior on a daily or weekly basis. Frequent occurrence of challenging behavior can result in social exclusion.

Interventions to increase caregiver's sensitive responsiveness, attunement, and emotion recognition in people with V-S/PID have proven to be successful. However, due to high staff turnover rates, the long-term impact of these, often time-intensive, interventions is likely limited. Interventions using modern technology might offer similar support in a less time-intensive manner. Since emotional arousal influences the physiological balance of the autonomic nervous system (ANS), sensor technologies measuring physiological signals can reflect emotional arousal. Detecting alterations in the arousal levels of people with V-S/PID using these sensor technologies may enable the caregiver to become more sensitive and responsive.

The aim of this thesis is twofold. The first part is the development of a monitoring system to support caregivers in better noticing, understanding, and interpreting the communicative behavior of people with V-S/PID. Secondly, this monitoring system is validated on measurement accuracy and its effect on the quality of interaction. It is hypothesized that through displaying physiological signals, caregivers become more aware of the client's arousal levels and take a closer look at the client's communicative behavior to interpret this arousal level. Due to a heightened awareness, caregivers might be able to attune better to this behavior, giving the client more opportunity for development and less cause for the occurrence of challenging behavior.

The monitoring system is developed in three iterations. The first iteration validated the underlying theory of emotional arousal influencing the physiological balance of the ANS with people with

V-S/PID. This first iteration also explored the design requirements for the monitoring system, which were validated and fine-tuned in the second iteration. The first and second iteration aimed at the home environment, while the third iteration explored the monitoring system in a new context: the institutional environment. This third iteration - the Bioresponse system - was evaluated on measurement accuracy and its effects on the quality of interaction.

The system's accuracy is tested with both subjects without disabilities and with adults with V-S/PID. In the first experiment, physiological data of twenty-two participants was collected over three relaxation tasks and three stressor tasks. The system's measurements of (emotional) arousal are compared to the subject's self-report of the experienced (emotional) arousal. In a pilot test, two adults with V-S/PID were observed in their interaction with one of their caregivers. The system's measurements are compared to behavioral observations of the adults with V-S/PID.

The effects of the Bioresponse system on the quality of interaction are evaluated in a randomized multiple baseline study. The effectiveness of this system is determined by measures of the caregiver's sensitive responsiveness, the client's joint attention behaviors and challenging behavior, and the dyad's affective mutuality. This study consisted of a baseline phase (with varying lengths), an intervention phase, and a follow-up phase. Four caregiver-client dyads from two Dutch organizations that provide support and care for people with visual and/or intellectual disabilities, each participated in 21 measurements.

The three design iterations, the design evaluations, and the accuracy and effect studies have generated insights relevant for both research and design involving monitoring systems. The Bioresponse system has proven to be accurate with people without disabilities. The accuracy of the system, when compared to behavioral observations of adults with V-S/PID, was low. However, since the challenges to interpret the client's subtle communicative behavior are the reason for the development of the Bioresponse system, a low agreement is to be expected. This study has highlighted the need for a better understanding of the physiological data of people with V-S/PID. Although the randomized multiple baseline study's intervention did not work as intended and no conclusions on the system's effectiveness can be provided, it has provided the opportunity to use the Bioresponse system for an extended period of time in the context of care organizations and thereby generated lessons learned relevant for future studies and design developments.

Long-term and repeated research with larger samples is required for solid conclusions on the effect of a Bioresponse system on the quality of interaction. However, this research did show that the Bioresponse system has the potential to positively influence the quality of interaction between professional caregivers and adults with visual and severe or profound intellectual disabilities.

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Chapter 1 Introduction

Communication and interaction are vital parts of our daily life and are the foundation for building relationships. Communication allows for the exchange of information and the sharing of thoughts, ideas, and feelings (Oxford dictionary, 2019; Cambridge dictionary, 2019). Experiencing a communication impairment imposes considerable challenges for inclusion in society and affects one's quality of life. A communication impairment or a communication disability means experiencing difficulties in creating, conveying, receiving, and understanding messages (World Health Organization, 1980). Not only has a communication impairment consequences for expressing oneself, but it also influences the interaction with others. Interaction is the process of communicating with and reacting to each other (Cambridge dictionary, 2019). Experiencing difficulties in sending, receiving, or understanding a message may jeopardize the success of an interaction.

Intellectual disabilities have a high prevalence among persons with communication impairments (Martin, O'Connor-Fenelon, & Lyons, 2010). Intellectual disability (ID) is characterized by significant cognitive, emotional, and adaptive skill deficits (Lecavalier & Butter, 2010; Belva, Matson, Sipes, & Bamburg, 2012). Adaptive skills are required for an optimal everyday living and include communication and socializing skills (Belva et al., 2012). Social skills enable healthy relationships, independence, and coping with stress (Lecavalier & Butter, 2010; Smith & Matson, 2010). Based on a meta-analysis of published research involving ID, Maulik, Mascarenhas, Mathers, Dua, and Saxena (2011) estimate a world-wide prevalence of ID of 10.37/1000 population. The estimated prevalence of ID in the Netherlands is 0.85%, with approximately 142,000 persons with an IQ below 70 (Volksgezondheid en Zorg, 2019; Vereniging Gehandicaptenzorg Nederland, 2019).

Intellectual disabilities can be classified into four categories: mild (intermittent support level needed), moderate (limited support level needed), severe (extensive support level needed), and profound (pervasive support level needed) (Adams & Oliver, 2011; Shree & Shukla, 2016). This thesis focuses on persons with "Ernstige Meervoudige Beperkingen (EMB)" or in English profound intellectual and multiple disabilities (PIMD) (Nakken & Vlaskamp, 2007; Maes et al., 2020). EMB is a complex combination of severe intellectual (IQ lower than 25 and developmental age of 24 months or less), auditive and/or visual, and motoric disabilities (Platform Ernstig Meervoudig Gehandicapt, 2019a). There are approximately 10,000 persons with EMB in the Netherlands, and about 9000 persons with EMB live in a home of an organization specialized in care and support for persons with ID and/or additional impairments (Vereniging Gehandicaptenzorg Nederland, 2019).

Individuals with severe or profound intellectual disabilities (S/PID) mostly communicate non-verbally and with limited symbolism. They tend to rely on gestures, eye gaze, body language, facial expressions, and vocalization to express themselves (Kobayashi, Nunokawa, & Ooe, 2009; Munde, Vlaskamp, Ruijssenaars, & Nakken, 2009). This communicative behavior can be challenging to understand for parents and professional caregivers (Hostyn & Maes, 2009). As technology is quickly evolving, new ways of communicating and interacting with others are being developed continuously. Augmentative and alternative communication (AAC) devices have emerged to provide persons with communication impairments (and motoric disabilities) with a means to express their wishes (Lancioni, Singh, O'Reilly, Sigafoos, & Oliva, 2014). One common AAC device is a microswitch — a sensor that is activated with a simple movement and allows persons with S/PID to control environmental stimuli, such as music, photos, videos, sounds, or lights. Speech-generating devices have been used to provide a pre–recorded request for attention or a specific item and can generally be activated by pressing a picture of this item (Lancioni et al., 2014). This thesis, however, explores how technology can support parents and professional caregivers in their interaction with persons with S/PID.

1.1 Problem Definition

Successful interaction, in which the interaction partners share attention, engagement, and interests (Hostyn, Neerinckx, & Maes, 2011), results in feelings of contentment, appreciation, and joy (Hostyn & Maes, 2009). Sensitive responsiveness is one of four components that are key to successful interaction with persons with S/PID. Sensitive responsiveness refers to a dyad correctly observing each other's communicative signals and responding accordingly (Hostyn & Maes, 2009). It can be challenging for caregivers to read and interpret the subtle communicative behavior of individuals with S/PID and to respond adequately to this behavior (Munde et al., 2009; Adams & Oliver, 2011). Although having the best intentions, caregivers in residential institutions are often not reacting sensitive enough to the client's signals (Maes, 2011). Yet, acting sensitively to the client's signals enables caregivers to prevent high levels of stress for the client and allows the client to learn new (coping) behavior within a safe environment (Sterkenburg, Schuengel, & Janssen, 2008).

Another essential factor contributing to successful social interactions is joint attention (Hostyn & Maes, 2009). Joint attention refers to a mutual awareness of sharing a focus of attention for an object or event between interaction partners (Bigelow, 2003). In individuals with S/PID, the development of joint attention is jeopardized. They tend to show little communicative behavior to attract the attention of their caregivers and often engage in interactions by responding to communication cues from others (Hostyn et al., 2011). They are more inclined to use their interaction partner as a means to reach a goal than to share their experiences or observations, compared to peers without disabilities (Olsson, 2005). It can be challenging for caregivers to understand, follow or direct the attention of individuals with S/PID, which complicates the establishment of interactions with a joint focus of attention (Hostyn et al., 2011).

The third element that contributes to successful interactions with persons with S/PID is co-regulation. Co-regulation covers concepts of mutuality in participation and understanding, attunement to the feeling state of the interaction partner, reciprocity, and turn-taking (Hostyn &

Maes, 2009). It is based on openness to, respect for, and acknowledgment of the partner and his/her contribution (Olsson, 2004). Attunement between interaction partners may be complicated due to the less distinct emotional expressions from persons with S/PID (Adams & Oliver, 2011). Forster and Iacono (2014) suggested that the frequency of displaying attunement behaviors might be low for individuals with S/PID as these individuals experience difficulties expressing the common indicators such as motoric behavior and attention. As a result of the subtlety and briefness of their attunement behavior, caregivers may easily overlook this behavior (Forster & Iacono, 2014). Another perspective describes co-regulation as "*the process by which relationship partners form a dyadic emotional system involving an oscillating pattern of affective arousal and dampening that dynamically maintains an optimal emotional state*." (p. 202, Butler & Randall, 2012). This perspective suggests that co-regulation occurs on an unconscious level through biological processes. To provide an example of a co-regulatory process: The peripheral temperature of an infant decreases when the infant is stressed. Upon noticing the infant's stress, the parent responds by increasing his/her peripheral temperature (IJzerman et al., 2015; Vinkers et al., 2013). As these biological processes are not inhibited for individuals with S/PID, this form of co-regulation is likely to be present in the interaction between caregivers and persons with S/PID.

The last key component influencing the success of social interactions is emotion (Hostyn & Maes, 2009). Caregivers have to rely on behavioral observations to interpret their client's emotions (Vos, De Cock, Petry, Van Den Noortgate, & Maes, 2013). The challenge lies in identifying the subtle, non-verbal expression of emotions in clients with S/PID (Adams & Oliver, 2011). Research has shown that behavioral observation can be reliable to interpret emotions, but also that observations can differ largely between caregivers and that the interpretation may depend on the context wherein this behavior is shown (Vos et al., 2013).

Severe and profound intellectual disabilities are associated with a high prevalence of visual impairment, hearing impairment, or a combination of the two (Evenhuis, Theunissen, Denkers, Verschuure, & Kemme, 2001). These additional impairments add to the complexity of the communication between client and caregiver (Blain-Moraes & Chau, 2012). A lack of eye contact and gaze following hinders both interaction partners in noticing whether they hold each other's attention. Attuning between interaction partners is complicated, when visual impairments occur, due to less distinct emotional expressions and the absence of reciprocal emotional responses (Van den Broek et al., 2017). This subtle communicative behavior may lead to misunderstanding or ignoring the client's needs and wishes (Hostyn & Maes, 2009).

The previous paragraphs have outlined how communication impairments can have severe implications for the quality of interaction between persons with visual and severe/profound intellectual disabilities (V-S/PID) and their caregivers. Communication impairments can also have a considerable impact on the client's well-being, as this impairment is associated with challenging behavior (Lecavalier & Butter, 2010; Poppes, van der Putten, & Vlaskamp, 2010). Challenging behavior is described as culturally abnormal behavior that causes a risk for social exclusion or physical health due to the intensity, duration, or frequency of this behavior (Poppes et al., 2010). Challenging behavior hinders the individual's physical and social development. The risk for the occurrence of challenging behavior is three to five times higher for individuals with

ID than for the population without disabilities (Poppes et al., 2010; Denis, Van Den Noortgate, & Maes, 2011). Individuals with S/PID show challenging behavior on a daily or weekly basis (Poppes et al., 2010). It has been suggested that individuals with S/PID use challenging behavior to attract attention from their caregivers or to escape from unpleasant situations (Lecavalier & Butter, 2010).

1.2 Research opportunities

A better understanding of the subtle communicative behavior of clients with V-S/PID may improve the caregiver's sensitive responsiveness and attunement behavior and may offer more opportunities for their clients to develop joint attention behaviors and reduce the occurrence of challenging behavior. Interventions, such as video feedback interventions (Damen, Kef, Worm, Janssen, & Schuengel, 2011; van den Broek et al., 2017), have successfully improved caregiver's sensitive responsiveness, emotion recognition of clients with V-S/PID, and attunement behavior. However, due to quick turnovers in staff, the benefits of these time-intensive interventions may be limited (Adams & Oliver, 2011). Technology that can be introduced without requiring intensive training could be beneficial in supporting caregivers to better notice, interpret, and understand the subtle communicative behavior of their clients. Since stress responses and emotional arousal influence the physiological balance of the autonomic nervous system (Mokhayeri, Akbarzadeh-T, & Toosizadeh, 2011), sensors that monitor physiological signals can be used to measure and visualize stress and emotional arousal. Seeing the alterations in the client's arousal levels as measured by the sensors may invite caregivers to observe the client's behavior more closely and may lead to discovering communicative signals from the client, perhaps even including signals they did not notice before.

1.3 Research objectives

The aim of this thesis is twofold. The first objective is to develop a monitoring system that can support parents and professional caregivers in their interaction with clients with visual and severe/profound intellectual disabilities (V-S/PID). The development is concerned with the design of the system, verification of the underlying theory, verification of the design decisions, and the system's accuracy. This objective is described in the first research question:

1. How to design a monitoring system that supports parents and professional caregivers in their interaction with persons with visual and severe/profound intellectual disabilities (V-S/PID)?

Relevant subquestions are:

a. What are the design requirements for a monitoring system that is used in the daily environment of persons with V-S/PID?

b. Can technologies, developed to measure (emotional) arousal for persons without disabilities, also measure (emotional) arousal for persons with V-S/PID?

c. What are the (requirements for the) components that compose a monitoring system for persons with V-S/PID?

d. What are the requirements for marketing a monitoring system for persons with V-S/PID?

The second objective is to determine the system's connection to behavioral observation and to evaluate the social validity and the effectiveness of the monitoring system with caregivers and clients with V-S/PID. The monitoring system is valued as effective when the caregiver's sensitive responsiveness, the client's joint attention behavior, and the dyad's affective mutuality have increased, while the occurrence of the client's challenging behavior has decreased. It is expected that through monitoring physiological signals, which reflect the client's arousal levels, caregivers become more aware of the client's subtle communicative behavior. Due to this heightened awareness, caregivers might be able to react more adequately and attune better to this behavior, giving the client more opportunity for development and expression of joint attention behaviors. The second objective is formulated in the second research question:

2. What are the effects of a monitoring system that supports parents and professional caregivers in their interaction with persons with visual and severe/profound intellectual disabilities (V-S/PID)?

Relevant subquestions are:

a. How accurately can the monitoring system measure (emotional) arousal?

b. What is the relationship between (emotional) arousal as measured by the monitoring system and the (emotional) arousal as observed in the client's behavior?

c. What is the social validity of the monitoring system for professional caregivers?

d. What is the effect of the monitoring system on the interaction between professional caregivers and persons with V-S/PID as measured by the caregiver's sensitive responsiveness, the client's joint attention behavior, the client's challenging behavior, and the dyad's affective mutuality?

An iterative approach, following the spiral model of Boehm (1988), was used to answer these research questions (Figure 1.1). Each cycle in this iterative approach started by exploring and expanding the design requirements (research subquestion 1a). The design requirements were then explored in several concepts and finally resulted in a prototype. This prototype was evaluated with users to validate the design requirements. The evaluation of the first iteration not only aimed to validate the design requirements but also aimed at validating the underlying theory (research subquestion 1b). The evaluation of the third iteration consisted of three parts: an experiment, a pilot study, and a randomized multiple baseline study. The experiment was done with non-disabled subjects to verify the accuracy of the system by comparing the system's measurements with self-reports (research subquestion 1c). The pilot test and the randomized multiple baseline study both involved clients with V-S/PID. The pilot test compared the system's measurements with behavioral observations of clients with V-S/PID (research subquestion 2a). The randomized multiple baseline study examined the effects of the third system on the interaction between caregivers and adults with V-S/PID

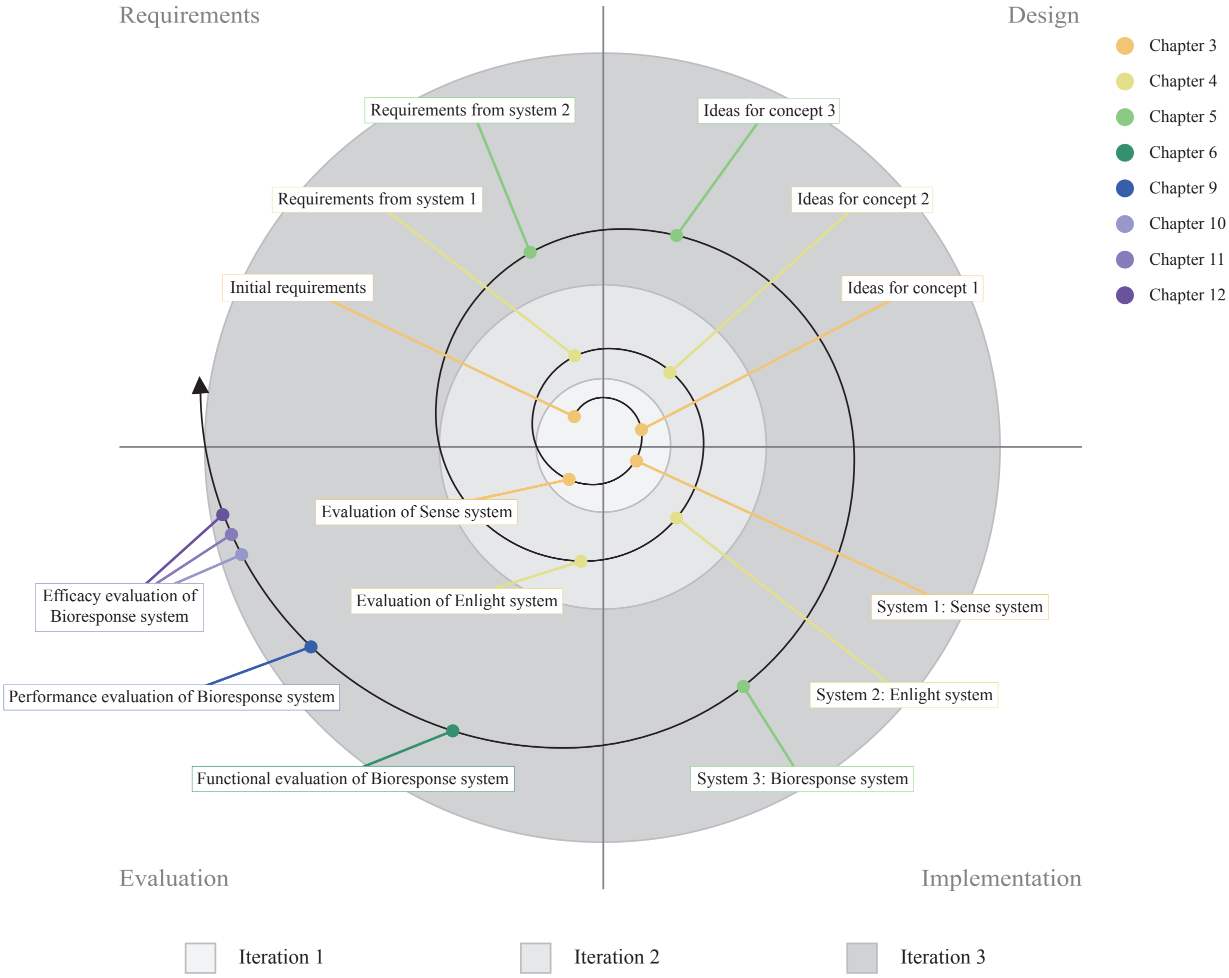


Figure 1.1 Spiral model of the iterative approach to answering the research questions.

(research subquestion 2b and c). At the end of the third cycle, two guidelines — a guideline for the development of a monitoring system (research subquestion 1d) and a guideline for implementing the monitoring system (research subquestion 1e) — were formulated based on the experiences from this iterative approach.

1.4 Thesis outline

This thesis is divided into two parts. Each part addresses one research question. The first part considers the design of the monitoring system, starting in Chapter 2 with the background information on the theories that are the foundation for the design. Those theories are validated with the first iteration of the monitoring system — the Sense system — which is described in Chapter 3. The Sense system also served as a tool to explore the design requirements with three parents and their children with Prader–Willi syndrome (PWS). Chapter 4 discusses the second iteration — the Enlight system. The Enlight system incorporated the design requirements found with the Sense system and was used to fine-tune these design requirements with parents and their children with PWS in their home environment. The current version — the Bioresponse system — is described in Chapter 5. This version integrated the results from the Enlight and the Sense systems and explored a new context — including professional caregivers and adults with V-S/PID in an institutional environment. Finally, a guideline for the development of a monitoring system based on the experiences with the Sense, the Enlight, and the Bioresponse systems and a guideline for implementing a monitoring system are provided in Chapter 6.

The second part of this thesis addresses the validation of the Bioresponse system (the iteration that is described in Chapter 5). This part starts with a vision for the contribution of monitoring systems, like the Bioresponse system, to transition research from the laboratory environment into the field (Chapter 7). The Bioresponse system's accuracy is validated with an experiment with non-disabled subjects since these subjects could verify the Bioresponse system with self-reported measures. Chapter 8 reports on the results of this experiment. The discussion of the Bioresponse system's validation continues with the outcomes of a pilot test involving persons with visual and severe/profound intellectual disabilities (V-S/PID), in which behavioral observations were used to verify the Bioresponse system (Chapter 9). The Bioresponse system's social validity and the effects on the quality of interaction between professional caregivers and their clients with V-S/PID were studied with a randomized multiple baseline design. The social validity of the Bioresponse system is reported in Chapter 10. Chapter 11 addresses the effects on the caregiver's sensitive responsiveness and the client's challenging behavior. The effects on the client's joint attention behaviors and the dyad's affective mutuality are discussed in Chapter 12. In order to present a coherent story on the development and the validation of the monitoring system, the studies reported in this thesis are not ordered chronologically. Figure 1.2 visualizes the chronological order of the monitoring system's development and validation. Finally, the thesis is concluded with a discussion on the design and research results, the limitations, and the implications for future design and research (Chapter 13).

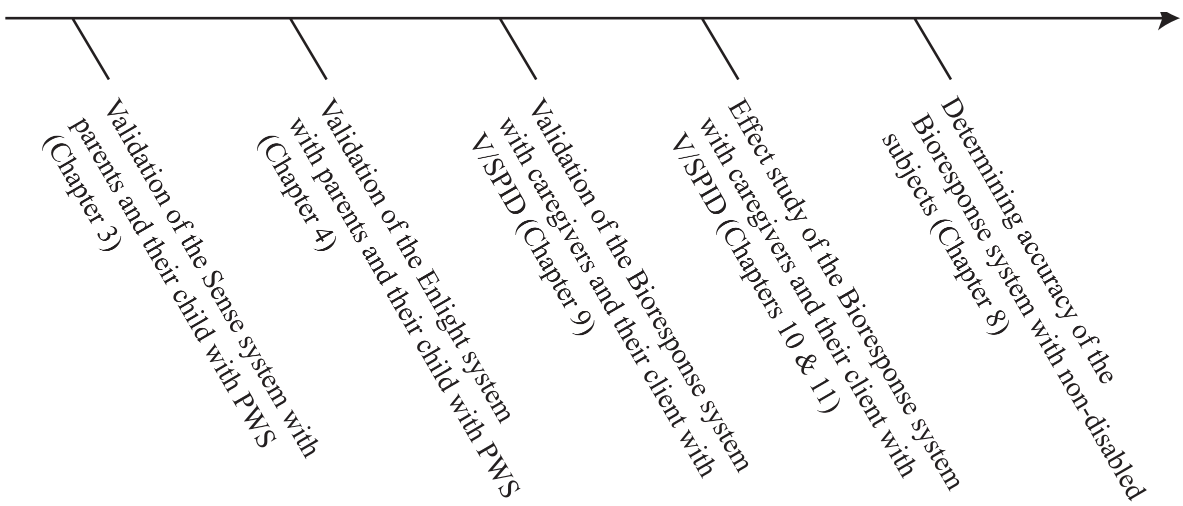


Figure 1.2 The Bioresponse system's evaluation studies in chronological order.

PART I

DESIGNING THE BIORESPONSE SYSTEM

2

Chapter 2 Background

The first objective of this thesis is to develop a monitoring system that can support caregivers in better noticing, understanding, and interpreting the subtle communicative behavior of persons with visual and severe/profound intellectual disabilities (V-S/PID). Generalized arousal in the central nervous system (CNS) is the driving force behind behavior (Pfaff, Ribeiro, Matthews, & Kow, 2008). Arousal — a combination of generalized arousal and specific arousal, such as hunger, fear, and pain (Pfaff et al., 2008) — influences bodily responses (Mokhayeri, Akbarzadeh-T, & Toosizadeh, 2011; Sharma & Gedeon, 2012). Although individuals with V-S/PID may experience difficulties expressing their needs, wishes, and feelings, their bodily reaction to arousal is similar to the bodily reaction of non-disabled people. Monitoring those bodily responses of persons with V-S/PID may allow caregivers to observe alterations in arousal they might not have perceived from behavioral observation.

2.1 Physiological signals

Bodily responses can also be referred to as physiological signals. Technically, all biological responses are physiological signals, including brain activity (although more commonly referred to as neurophysiology), facial expressions, vocal patterns, and body chemistry. However, in literature, physiology generally means those bodily responses that are mediated by the autonomic nervous system (ANS) (Healey, 2014). The ANS transfers impulses from the CNS to the organs, enabling the body to adapt to changes (Mokhayeri et al., 2011). The ANS can be divided into two subsystems: the sympathetic nervous system (SNS) and the parasympathetic nervous system (PNS) (Mokhayeri et al., 2011; Sharma & Gedeon, 2012). The SNS increases activity, while the PNS decreases activity (Sharma & Gedeon, 2012). These two systems dynamically balance each other. When one system is activated, the activity of the other is usually dampened (Tartarisco et al., 2012).

Physiological signals can be measured with the help of physiological sensors. Physiological sensors transform a physical phenomenon into an electrical signal (Al Osman, Eid, & El Saddik, 2014). Physiological signals can be used as a measure of psychological phenomena, like affect (Healey, 2014), stress (Yu, Funk, Hu, Wang, & Feijs, 2018), or workload (Charles & Nixon, 2019). The difficulty in using physiological signals as a measure for psychological phenomena is that the ANS is not exclusively designed to mediate psychological phenomena. The ANS is also responsible for vital processes such as metabolism and regulation of body temperature. Differentiating alterations in physiological signals as a result of psychological phenomena from alterations caused by vital processes can, therefore, be challenging (Picard, 1997). The physiological signals that are measurable include electrodermal activity, cardiac activity, brain activity, muscle activity, and respiration (Healey, 2014; Sharma & Gedeon, 2012). These five signals are described in more detail below.

2.1.1 Electrodermal activity

Electrodermal activity (EDA) is a collective term for all electrical properties of the skin. EDA measurements can be distinguished into two categories: (1) endosomatic measurements (recorded without external currents), and (2) exosomatic measurements (recorded with the use of external currents). The exosomatic measurements can be further divided into two subcategories of alternating current (AC) measurements and direct current (DC) measurements. AC recordings can be used to collect either skin impedance (SZ) or skin admittance (SY), while DC recordings are used to measure skin resistance (SR) or skin conductance (SC). Endosomatic recording methods are used to collect skin potential (SP) data (Boucsein, 2012).

Two elements can be distinguished in the EDA data: the tonic element, also referred to as level, and the phasic element, also called responses. These two elements can be observed in all the mentioned EDA measures of SP, SZ, SY, SR, and SC (Boucsein, 2012). The EDA level (EDL) is an indication of the overall level of sympathetic arousal. EDA responses (EDR) reflect stimulus-specific responses (e.g., hearing one's name) or non-specific responses (e.g., a person's thoughts) (Benedek & Kaernbach, 2010a).

Skin conductance (SC) is often used as a measure for psychological phenomena. SC can reflect the alterations in the skin's electrical properties caused by sweat secretion (Ogorevc, Geršak, Novak, & Drnovšek, 2013). Dry skin is an insulator. As a result of sweat secretion, the conductivity of the skin changes (Healey, 2014). The best locations to measure SC are the locations with the highest density of sweat glands, which can be found on the sole and dorsum of the foot, on the forehead, cheek, palm, and forearm (200–600 per cm^2) (Benedek & Kaernbach, 2010b; Ogorevc et al., 2013). As sweat gland activity is part of the sympathetic activity, SC recordings only reflect the activity of the SNS, and not the activity from the PNS (Healey, 2014). The SNS is influenced by psychological phenomena like emotional arousal, stress, and workload; therefore, SC recordings can be used as a measure for these psychological phenomena (Ogorevc et al., 2013).

2.1.2 Cardiac activity

Cardiac activity can be observed through two different methods: electrocardiography (ECG) or photoplethysmography (PPG). ECG measures the electrical changes that are detectable on the surface of the skin and are caused by the polarization of the heart chambers (Healey, 2014). The heart pumps blood into the peripheral blood vessels, thereby causing the blood vessels to expand and shrink. PPG illuminates the skin and underlying tissues to detect the changes in light absorption caused by the expansion and contraction of the blood vessels (Yu et al., 2018). Two main measures that generally are extracted from either ECG or PPG are heart rate (HR) and heart rate variability (HRV) (Healey, 2014).

ANS activity is well reflected in the measure of HR since both the SNS and the PNS influence HR. The SNS causes an accelerated HR, while the PNS slows HR down. The acceleration of HR is often perceived as related to stress, while the slowing down of the HR is often considered as a reflection of relaxation (Healey, 2014). HRV refers to the varying interval between heartbeats. HRV consists of non-linear measures and linear measures that are either time domain or frequency domain (Charles & Nixon, 2019). Commonly, the ratio of low-frequency to high-frequency power is used as an HRV measure. Other measures include cardiac coherence and standard deviation of inter-beat interval (Yu et al., 2018; Charles & Nixon, 2019). HRV is often used as a measure for stress and mental workload (Xu, 2014), as stress is associated with increased low frequency and decreased high-frequency components of heartbeat interval signals (Mokhayeri et al., 2011).

2.1.3 Brain activity

Brain activity can be measured with functional magnetic resonance imaging (fMRI) or electroencephalography (EEG). fMRI commonly uses blood oxygenation level-dependent (BOLD) imaging, which detects differences in magnetization properties of hemoglobin that has absorbed oxygen (oxyhemoglobin) and hemoglobin that has not absorbed oxygen (deoxyhemoglobin) (Arthurs & Boniface, 2002). Studies using fMRI have connected specific brain regions to emotions, e.g., fear specifically engaged the amygdala (Phan, Wager, Taylor, & Liberzon, 2002). However, fMRI is less common in physiological signal research, since fMRI scanners are bulky machines that require a dedicated room to facilitate measurements. Although less accurate than fMRI, EEG measurements are more common in physiological signal research due to the required equipment being more readily available (Healey, 2014). EEG measures the electrical changes that are detectable on the surface of the head. A full EEG uses 128 electrodes placed on the surface of the head and can detect emotional valence (referring to the value of the emotion, which can be neutral, positive, or negative) (Healey, 2014). EEG units with two to four channels are also available and are commonly used in biofeedback applications. The downside of EEG measurements is that they can only be used in a lab since EEG is sensitive to electric noise, sound, motion, and muscle activity (Healey, 2014).

2.1.4 Muscle activity

Muscle activity can be measured with electromyography (EMG), which monitors the altering of surface voltage as a result of muscle contractions and relaxation (Sharma & Gedeon, 2012; Healey, 2014). The trapezius muscle in the shoulder is a common location for an EMG measurement that can detect stress (Sharma & Gedeon, 2012). EMG measurement of facial muscles can be used to identify affect through facial expressions (Healey, 2014). In affect monitoring, EMG can be used for both detecting emotional arousal and for detecting emotional valence (Healey, 2014).

2.1.5 Respiration

Respiration (RSP) can be measured through respiration rate, respiration depth, airflow, volume, or gas exchange of the lungs. Airflow and gas analysis are measured with the use of a mask that is placed over the mouth and nose (Healey, 2014; Charles & Nixon, 2019). Respiration rate and depth can be monitored with a strap around the chest or abdomen that measures chest/abdomen expansions and contractions (Yu et al., 2018; Charles & Nixon, 2019). Other ways of measuring chest expansions are through a Hall Effect sensor or capacitance sensor (Healey, 2014). Emotional arousal and physical activity are associated with a higher respiration rate and more respiration depth, while slower and shallower respiration is connected with relaxation (Healey, 2014). Respiration rate is often used as a measure for mental workload (Charles & Nixon, 2019). Since respiration influences the heart rate, respiration measurements are often combined with cardiac activity measurements (Healey, 2014).

2.1.4 Applications of physiological signal monitoring

Kocielnik, Sidorova, Maggi, Ouwerkerk, and Westerink (2013) applied an unobtrusive monitoring system for continuous monitoring in the work environment to stimulate employees to reflect on their work stress. Xue and colleagues (2019) designed AffectiveWall, a shared display, which anonymously visualizes both individual and collective stress in teams. Healey and Picard (2005) used a monitoring system to detect driver's stress on a route through Boston. Hedman and colleagues (2012) used physiological signals to support therapists in optimizing the child's experience during occupational therapy with children with sensory challenges (e.g., autism and ADHD). Perugia and colleagues (2017) monitored EDA to gain better insight into the engagement of persons with dementia in activities.

2.2 Affective computing

One field of research known for its use of physiological signals is affective computing. Affective computing studies the ability of systems to automatically sense, interpret, and express affect (Tao & Tan, 2005). It also aims to validate existing models of emotion and to make computers more intelligent using models mimicking emotions (Picard, 1997). There are three main theories in defining emotions. The first theory is the James–Lange theory, which defines emotions as a mainly physiological reaction (Healey, 2014). According to this theory, emotions are generated in a bottom-up process, wherein physiological changes lead to the generation of an emotional state (James, 1894). The second theory is the Cannon–Bard theory, which describes emotions as a top-down process and to be primarily cognitive (Cannon, 1927). The third theory, the two-factor theory of emotion proposed by Schachter, states that emotions result from physiological reactions and the cognitive interpretation of these reactions (Healey, 2014).

Although researchers do not agree on a definition of what emotions are, they do agree on emotions existing of two aspects: a cognitive and a physical component (Picard, 1997). This physical component allows emotions to be measured with physiological signals. However, recognizing which emotion is measured in the physiological signals is difficult. The manner of inducing emotions and other bodily reactions, such as exercise, can influence the interpretation of the measurement. Moreover, not everyone experiences emotions in the same way or the same intensity (Picard, 1997).

Not only do researchers disagree on the definition of emotion, but they also disagree on the interpretation of emotions. One theory — the theory of basic emotions — assumes that there is a set of basic emotions that is the same across cultures. These basic emotions can be combined and used to explain other, more complex emotions (Ekman, 1999). Within the theory of basic

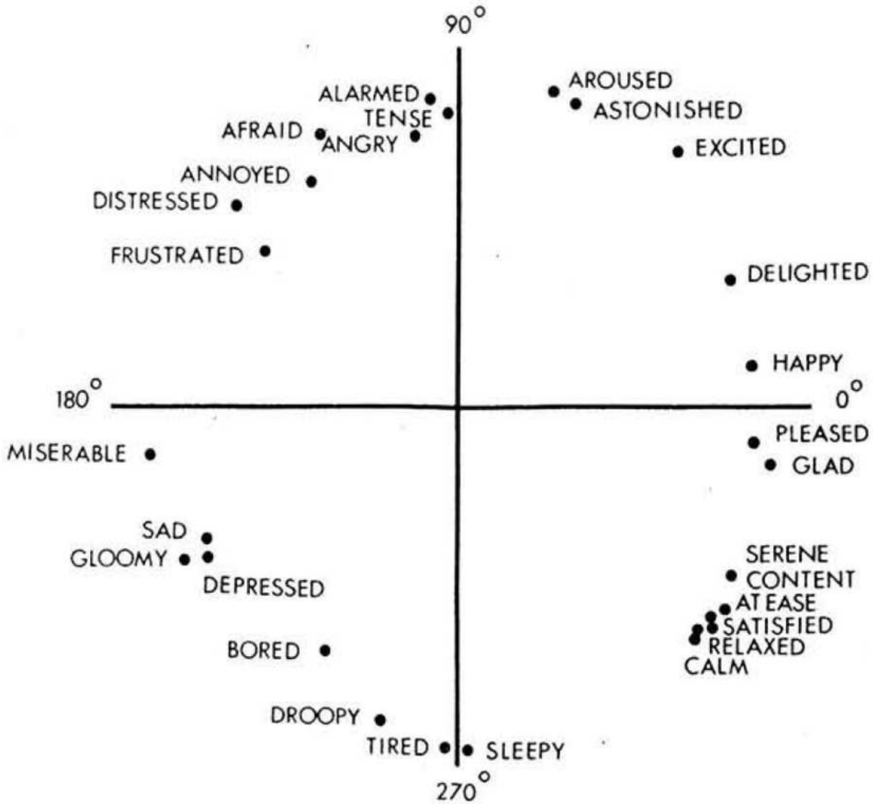


Figure 2.1 Russell's circumplex model of affect (from: Wang, Tan, & Miao, 2016).

emotions, there are multiple interpretations of which emotions compromise the basic emotions. Ekman, Friesen, and Ellsworth (1982) list six basic emotions: anger, disgust, fear, joy, sadness, and surprise. While James (1884) only defines four basic emotions: fear, grief, love, and rage. Another theory is the dimensional theory of emotion. In this theory, emotions are explained on two axes: arousal and valence, as demonstrated in Figure 2.1 (Russell, 1980). The last theory — the appraisal theory — states that the meaning of a particular stimulus for a specific person, in a specific context, and for a specific moment, elicits emotions. In this theory, alterations in emotions are the result of changes in the environment or new interpretations of the stimuli by the person (Ellsworth & Scherer, 2003).

2.2.1 Applications of affective computing

Liu and Picard (2005) build an interactive, health application for data collection, annotation, and feedback that is empathetic in its dialogue. Gravenhorst, Muaremi, Tröster, Arnrich, and Gruenerbl (2013), Valenza et al. (2013), and Puiatti, Mudda, Giordano, and Mayora (2011) developed monitoring systems to support the treatment of persons with a bipolar disorder. These systems aim at detecting the patient's mood and teaching them to prevent the occurrence of manic/depressive episodes. Vos, De Cock, Petry, Van Den Noortgate, and Maes (2013) studied the use of physiological signals as a supporting tool for behavioral observations to interpret the emotions of individuals with severe/profound intellectual disabilities (S/PID).

2.3 Biofeedback

Another research topic that relies on the measurement of physiological signals is biofeedback. Biofeedback is a self-regulating skill where individuals learn to control biological functions based on feedback provided by physiological sensors (Rovers, Feijs, van Boxtel, & Cluitmans, 2009). In clinical biofeedback, self-regulating skills are taught by trained therapists (Al Osman et al., 2014). In clinical settings, biofeedback is often used for relaxation training, stress management, pain management, and emotion regulation (Al Osman et al., 2014; Yu et al., 2018). Technological advancements have enabled the development of wireless and wearable sensors, and thereby have enabled the application of biofeedback in everyday environments, like the work or home environment, without the support of therapists (Al Osman et al., 2014; Yu et al., 2018).

A typical biofeedback loop exists of (1) measuring physiological signals with the use of sensors, (2) reinforcing the subject when a specific signal occurs, and (3) the subject adjusting this signal consciously (Demos, 2005). In their review, Yu and colleagues (2018) found that HRV, HR, RSP, and EDA are the most often used physiological signals in biofeedback systems. A typical biofeedback system consists of four components: (1) a sensor collecting physiological data, (2) a unit to transfer this data, (3) a unit to process this data, and (4) a unit to provide feedback on the data to the user (Yu et al., 2018). The most common types of feedback are visual feedback (graphs, diagrams, animations, virtual characters, ambient lights, etc.) and auditory feedback (changing the pitch or the interval between notes, different types of music, etc.) (Yu et al., 2018).

2.3.1 Applications of biofeedback

Biofeedback systems have been applied to several contexts: health care, therapy, sports, work, and home. Health applications of biofeedback have been used to treat headaches (Nestoriuc, Martin, Rief, & Andrasik, 2008), chronic pain (Sielski, Rief, & Glombiewski, 2017), and epileptic seizures (Nagai, Jones, & Sen, 2019). In a clinical context, biofeedback has been used to reduce anxiety disorders (Goessl, Curtiss, & Hofmann, 2017), trauma (Bell, Moss, & Kallmeyer, 2019), and to promote emotion regulation (Lobel et al., 2016). In sports, biofeedback has aided in improving performances (Perry, Shaw, & Zaichkowsky, 2011) and recovering from injuries (Rollo, Tracey, & Prapavessis, 2017). In the work and home environment, biofeedback systems have aimed at learning to manage everyday stress (Choi, Ahmed, & Gutierrez-Osuna, 2011; Giakoumis, Tzovaras, & Hassapis, 2013). In the field of intellectual disabilities (ID), biofeedback systems have been used to train the emotion regulation skills of sexual offenders with ID (Gray, Beech, & Rose, 2019).

2.4 Physiological signals and the interaction between caregivers and persons V-S/PID

As stated before, one of the objectives of this thesis is to develop a monitoring system that can support caregivers in better noticing, understanding, and interpreting the subtle communicative behavior of persons with V-S/PID. With a similar aim, Kobayashi, Nunokawa, and Ooe (2009) developed a system that measured the HR wave of persons with a severe motor and intellectual disability and provided caregivers with automatically detected information on alterations in HR (e.g., acceleration, deceleration, no response or error). They demonstrated the feasibility of this kind of system by comparing observed behavioral reactions with HR measurements. Also, Lima and colleagues (Lima et al., 2012, Lima, Silva, Amaral, Magalhães, & De Sousa, 2013) compared the ability to detect responses to stimuli in a child with profound intellectual and multiple disabilities using HR and motoric behavior observations. They noticed that the HR signal detected more responses to stimuli than the behavioral observations. Vos and colleagues measured HR, HRV, SC, RSP, and skin temperature (ST) during four positive and four negative stimuli and were able to discriminate between positive and negative stimuli for ST (Vos et al., 2012), HRV, and RSP (Vos et al., 2013), but not for HR and SC.

The systems described above have focused on either detecting the responses to specific stimuli or the emotional state of persons with (V)S/PID using physiological signals. Both aims require a controlled environment. Untargeted stimuli, such as movements (other clients or caregivers walking by), and background sounds (sounds from other clients, caregivers talking, radio playing, etc.), and activities that require extensive bodily movements or increased vital bodily processes influence the measured physiological signals. To be able to interpret the physiological signal(s) in relation to the provided stimuli or elicited emotions, untargeted stimuli and activities need to be avoided as much as possible. Although the detection of responses to specific stimuli and supporting the interpretation of emotional expression are highly valuable, their application to the daily, uncontrollable environment of persons with (V)S/PID is not yet feasible. As Vos et al. (2013) concluded: physiological monitoring with persons with (V)S/PID currently is too time-intensive and excludes too many situations for being a beneficial addition to emotion detection based on behavioral observation.

This thesis aims at the development and validation of a monitoring system that can be applied to the daily life of persons with V-S/PID. This monitoring system does not focus on detecting specific responses or emotional states. It informs caregivers of alterations in general arousal level (regardless if emotions or vital bodily processes cause it) and of all responses (both reactions to specific stimuli and non-specific responses). Including all arousal sources and all responses means that untargeted stimuli and activities can be included in the usage of the system. It also means that the interpretation of the physiological signal becomes more complex and that training preceding the usage of the system is required. This system aims to invite caregivers to take a closer look at the person with V-S/PID upon observing alterations in the physiological signal, and to take a moment to observe the person's environment. These observations could potentially reveal patterns in behavior and events in the environment that would otherwise go unnoticed, or perhaps even detect communicative signals from the person with V-S/PID that the caregiver did not notice before. Although the use of this system does not make training superfluous, the training is likely less time-intensive than an intervention, like a video feedback intervention.

Preface

In 2011, prof. P. Sterkenburg was approached by a parent of a child with Prader–Willi syndrome (PWS) with the question if modern technology could support the bonding between parents and their child with PWS. The Industrial Design department of the Eindhoven University of Technology and the Clinical Psychology department of the Vrije Universiteit Amsterdam collaborated in a project that aimed to answer this question. This project was the first step in the iterative process of developing a monitoring system for persons with visual and severe/profound intellectual disabilities (V-S/PID). The aim of this chapter is twofold. The first aim was to explore the design requirements for a monitoring system, thereby providing a first answer to research subquestion 1a "What are the design requirements for a monitoring system that is used in the daily environment of persons with V-S/PID?" The second aim was to validate the physiological signal's ability to reflect the child's (emotional) arousal level to provide an answer to the research subquestion 2a "Can technologies, developed to measure (emotional) arousal for persons without disabilities, also measure (emotional) arousal for people with V-S/PID?"

This chapter is based on: Frederiks, K., Croes, M., Chen, W., Bambang Oetomo, S., & Sterkenburg, S. (2015). Sense – a biofeedback system to support the interaction between parents and their child with the Prader-Willi syndrome: A pilot study. *Journal of Ambient Intelligence and Smart Environments, 7*(4), 449-459.

Chapter 3 First iteration: Sense system

3.1 Introduction

People feel a need to form close bonds with others. This is especially true for parents and children (Swain, Lorberbaum, Kose, & Strathearn, 2007). Young children seek comfort and safety from a caregiver in times of stress (Howe, 2006), which is a biological mechanism in infants for survival (Swain et al., 2007). Sensitive caregivers teach the child to cope with stress and to understand people's minds on emotional, behavioral, and intentional levels (Howe, 2006). Emotionally available caregivers who are responsive make sure the infant bonds securely. While an infant of a caregiver who is unpredictable and neglectful runs the risk of developing an insecure attachment (Swain et al., 2007). Children with such an insecure bond are prone to develop behavioral problems, such as angry, demanding, dissatisfied, needy, and provocative behavior (Howe, 2006).

The development of a secure bond between parent and child could be jeopardized by the presence of intellectual disabilities (ID). Children with ID are usually less reactive and less clear in their communicative signals. For parents, it is challenging to interpret this subtle communicative behavior and to respond accordingly (Janssen, Schuengel, & Stolk, 2002). Not being able to understand their child's needs and the experienced lack of interest in interaction from the child causes stress for parents. As a result of experiencing stress, parents become less sensitive to the communicative signals of their child (Howe, 2006). When the child's needs are unrecognized or misunderstood, the child becomes distressed (Howe, 2006). Experiencing stress results in children becoming less responsive to external stimuli (Janssen et al., 2002). This vicious circle could spiral down and threaten the bonding process further.

Another possible risk factor for an insecure attachment is the combination of ID with additional impairments or syndromes; for example, the Prader–Willi syndrome (PWS). PWS is a genetically determined neurodevelopmental disorder, first discovered in 1956 by Prader, Labhart, and Willi (Reddy & Pfeiffer, 2007). The estimated prevalence is 1/10,000–1/25,000 births (Albrecht & Buiting, 2010; Whittington & Holland, 2011) and it occurs in both sexes and all races (Priano et al., 2009). PWS is characterized by distinct facial characteristics (almond-shaped eyes, downturned angles of the mouth, and narrow bifrontal diameter), short stature, hyperphagia (an insatiable hunger), hypogonadism, mild to moderate intellectual disabilities, and behavioral problems (skin-picking, temper tantrums, and repetitive behavior) (Cataletto, Angulo, Hertz, & Whitman, 2011; Mann & Butler, 2009). In infancy, the main characteristics are severe hypotonia and lethargy (Cassidy & Driscoll, 2009). After six months, movement expression and muscle tone tend to increase, however persons with PWS will suffer from mild to moderate hypotonia throughout life (Paterson & Donaldson, 2003; Cassidy & Driscoll, 2009).

At the onset of childhood (approximately from the age of 2), characteristic behaviors (including temper tantrums, compulsive-like behaviors, and difficulties with change in routine), decreased growth velocity, and hyperphagia — causing excessive eating and obesity if uncontrolled — start to develop (Cataletto et al., 2011; Mann & Butler, 2009; Cassidy & Driscoll, 2009). In adulthood, the syndrome is characterized by repetitive, ritualistic, and compulsive behaviors, hyperphagia, hoarding of food, emotional lability, and psychosis (Cataletto et al., 2011; Mann & Butler, 2009).

As mentioned before, infants with PWS are likely to have severe hypotonia in the first six months after birth (Mann & Butler, 2009; Priano et al., 2009). Due to being hypotonic, the infants hardly cry or do not cry at all and express movement to a lesser extent (Cataletto et al., 2011; Paterson & Donaldson, 2003; Cassidy & Driscoll, 2009). Furthermore, children with PWS are excessively sleepy (Crespi, 2010; Haig & Wharton, 2003), and show decreased spontaneous arousal (Cassidy & Driscoll, 2009). These characteristics of PWS make it even more challenging for parents to interpret their child's communicative behavior. Although the infant experiences difficulties in expressing communicative behavior, the infant's autonomic nervous system (ANS) is still activated. Through measuring the activation of the infant's ANS, a monitoring system may provide additional cues. These additional cues might support parents in interpreting their child's communicative signals.

In this chapter, the design and evaluation of a monitoring system that supports the bonding process between parents and their child with PWS is described. This system, called Sense, measures the activation of the child's ANS with a skin conductance (SC) sensor. The signal of this sensor is then transmitted to a movement and color-changing actuator design to support parents in their interpretation of the child's communicative signals. Section 3.2 will describe the design of the Sense system. This section elaborates on the design process, the design concept, and the creation of the experience prototypes. The results of the system's evaluation with three parents and their children with PWS are discussed in section 3.3. Section 3.4 provides the

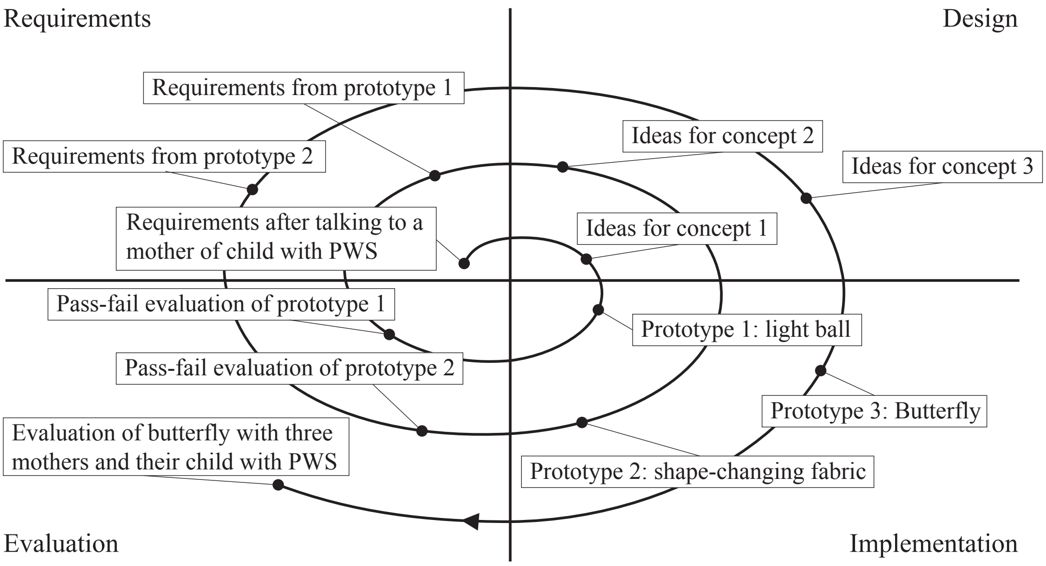


Figure 3.1 Spiral model of iterative design process of the Sense system.

discussion on the evaluation results, and the conclusion can be found in section 3.5.

3.2 Design

The design process of the monitoring system followed a spiral model (Boehm, 1988; p. 5, Hu, 2006) and consisted of three iterations (Figure 3.1). This iterative process is the inner circle (the lightest grey color) of Figure 1.1, where these details are hidden. At the start of the process, an expert — a mother of a child with PWS — provided the initial design requirements: (1) a monitoring system should trigger the parent's attention when the child is not able to do so himself/herself, and (2) a monitoring system should support parents during the interaction with their child. Based on these requirements, a monitoring system was proposed. The Sense system consists of a sensor that measures the child's arousal levels using physiological signals and an actuator design that represents the sensor's signal in a pleasant way.

3.2.1 Measurement of the child's arousal levels

For the Sense system, the physiological signal that measures the child's arousal levels was electrodermal activity (EDA). A Med–Storm pain monitor (Storm, 2012) was acquired from the Máxima Medical Center, Veldhoven, the Netherlands, to measure skin conductance (SC). SC is an EDA measure known to indicate (emotional) arousal (Bach, Friston, & Dolan, 2010; Das & Pal, 2011). It reflects the activity of the eccrine sweat glands, which are directed by the sympathetic nervous system, and measures changes in voltage over the skin's surface when a tiny constant current is applied (Das & Pal, 2011). The voltage amplitude is determined by the number of active sweat glands (Bach et al., 2010). The Med–Storm pain monitor requires the attachment of three sticky electrodes to the child's foot (Figure 3.2) and a wired connection to a laptop computer running dedicated software. The Med–Storm's sensor measurements range from 1 μS to 200 μS. For resistive measurements on 100 μS, the noise level is below 0.002 μS (Med–Storm Innovation AS, 2012). The skin conductance peak and the number of peaks per second are displayed in a sliding 15-second-window updated each second (Storm, 2012).

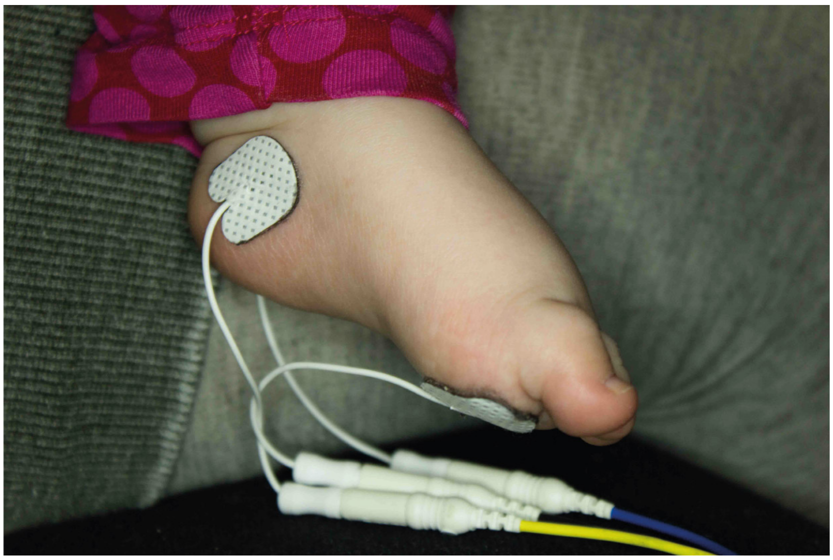


Figure 3.2 Attachment of the sticky electrodes from the Med–Storm pain monitor.

3.2.2 Representing the physiological signal

The standard visualization of the SC signal is a graph. For an expert, the graphical representation of the signal is accurate and precise in its information; however, for a layman, the graph might be a little overwhelming in the amount of information it provides and has an association with hospital equipment. For the Sense system, an alternative representation — not a graphical representation — was developed to make the information accessible for everyone and give it a friendly and fun appearance. In developing an alternative visualization, the core information of the graph had to be maintained. This core information was summarized to: an increase in the SC signal means an increase in one's general arousal level, and a decrease in the SC signal indicates a decrease in one's general arousal level. This alternative visualization of the SC signal's amplitude was explored in three iterations.

First iteration - Light

First, the characteristics of light were explored for their ability to reflect the SC signal's amplitude. Light can provide feedback by changing color or intensity. A low-fidelity prototype was created to study light as feedback. An (RGB) LED, controlled by an Arduino UNO, was inserted in a plastic ball, made opaque by sand-blasting the inside of the ball (Figure 3.3A). The brightness settings of a red LED were adjusted to explore feedback through light intensity. The brightness reflects the SC amplitude, and thus, the child's arousal levels: a brightness level of 255 indicated high arousal, a brightness level of 170 was used for medium arousal, and for low arousal the brightness level was set to 85 (Figure 3.3B). Light intensity as feedback reflects alterations in SC amplitude well when continuously observing the light. However, when the light has been out of sight — for example, seeing the light upon returning to the room — distinguishing the current level of intensity (e.g., observing the difference between medium or low intensity) is challenging, and requires additional information.

The same low-fidelity prototype was used for exploring the color feedback; however, the red LED was replaced by an RGB LED. Walters, Apter, and Svebak (1982) suggest that people associate long-wavelength (red) colors with high arousal and short-wavelength (blue) colors with low arousal. In the prototype, blue represented low arousal, purple was used for medium arousal, and pink indicated high arousal. Although color is more effective in its feedback than intensity — because it can be used without continuous observation (Figure 3.3C) — observing the state of medium arousal remained difficult. Another possible disadvantage is that the color reference taken from the study of Walters et al. (1982) did not take valence (referring to the value of the emotion, which can be neutral, positive, or negative) into account. The intuitive interpretation of the colors in relation to the child's emotions might, therefore, influence the interpretation of the SC amplitude (e.g., red being interpreted as angry as opposed to high arousal).

Second iteration - Shape change

The graphical representation of the SC signal can be described as a point that moves from left to right over time, and up and down to represent the arousal level. The second exploration

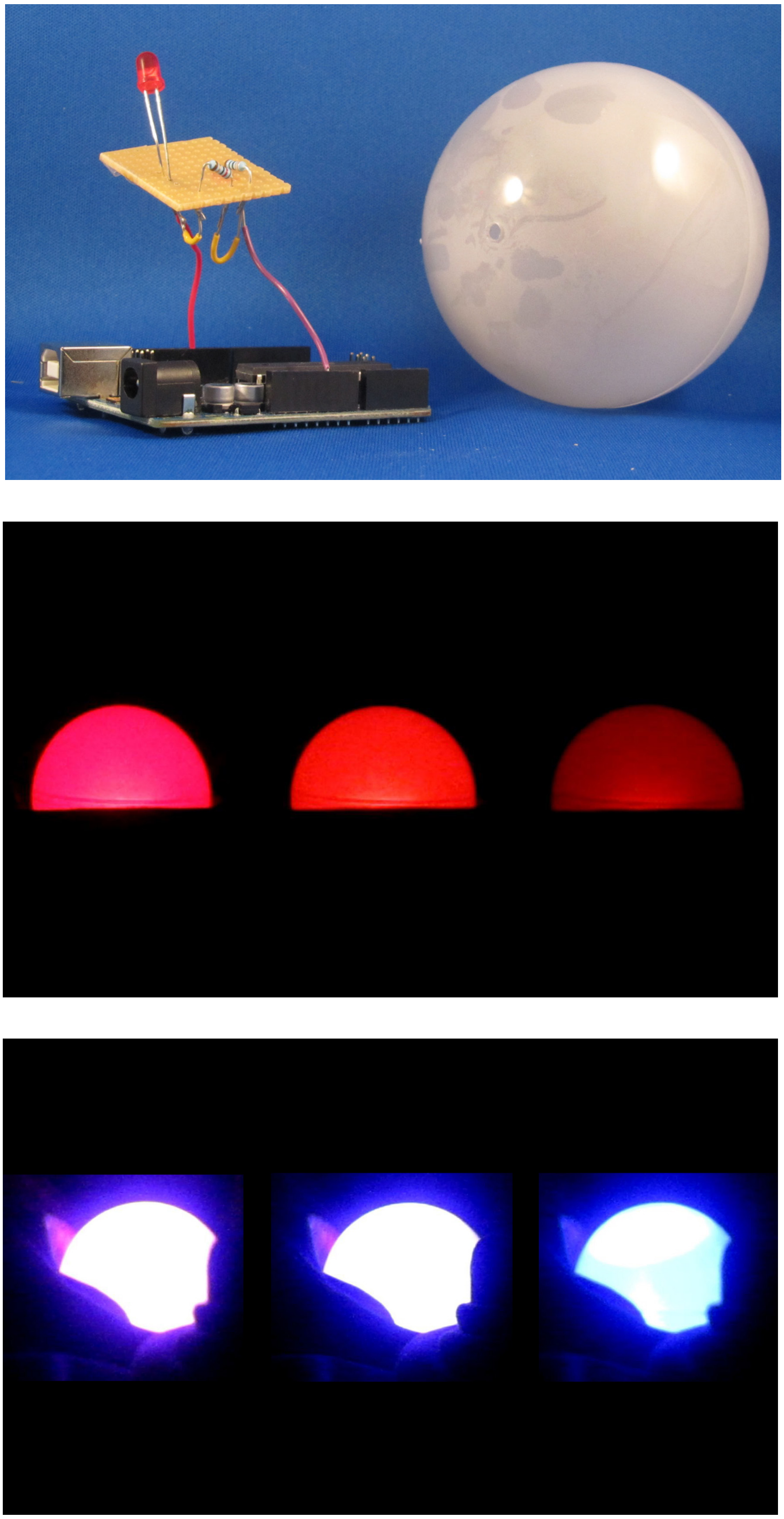


Figure 3.3 Exploring light as a feedback with a low-fidelity prototype.
Panel 3.3A: Light feedback prototype.
Panel 3.3B: Exploring light intensity as feedback. Left: high arousal; middle: medium arousal; right: low arousal.
Panel 3.3C: Exploring light color as feedback. Left: high arousal; middle: medium arousal; right: low arousal.

considered physical movement for representing the SC signal in a shape-changing object. Shape-changing objects are objects that physically change their shape, return to their original form, and can repeat the shape change (Rasmussen, Pedersen, Petersen, & Hornbæk, 2012). A physical movement of the graph's upward and downward movement was explored in a low-fidelity prototype: several sticks were placed underneath fabric causing the fabric to change in form (Figure 3.4). By slowly fading the newly created shape over time, it also indicated the arousal occurring over time. Like with the light feedback, the differences between arousal states (high, medium, or low) were difficult to distinguish. Moreover, remembering which shape belonged to which event, or discovering the most recent change when not continuously observing the object, is challenging. Another disadvantage of this feedback is that the technology, at the time of development, was not small enough to incorporate in a portable object. Therefore, the object becomes part of the environment instead of part of the interaction, resulting in the parent having to look at the product instead of looking at the child.

Third iteration - Light and Movement

Individually, neither light nor movement was effective in communicating the SC signal. Therefore, the next exploration generated ideas to combine light and movement. The starting point of this exploration was semantic differentials. Semantic differentials — opposing word pairs (e.g., hard–soft) — have often been used to study aspects of product form-giving (Hsu, Chuang, & Chang, 2000). The semantic differentials considered in this exploration included up–down, slow–fast, big–small, and open–closed. The open–closed differential was highlighted as it not only had the potential to represent the SC signal but also to represent the child's communicative signals. When the child is calm (thus a low arousal state), (s)he presents little communicative signals. Similarly, a closed shape provides little information. High arousal was associated with many communicative signals from the child and an open shape showing ample information. An example of a butterfly illustrated this open–closed differential. When the wings of a butterfly are closed, the patterns on the wings are hardly visible; however, when the butterfly opens its wings, all kinds of colors and patterns become apparent.

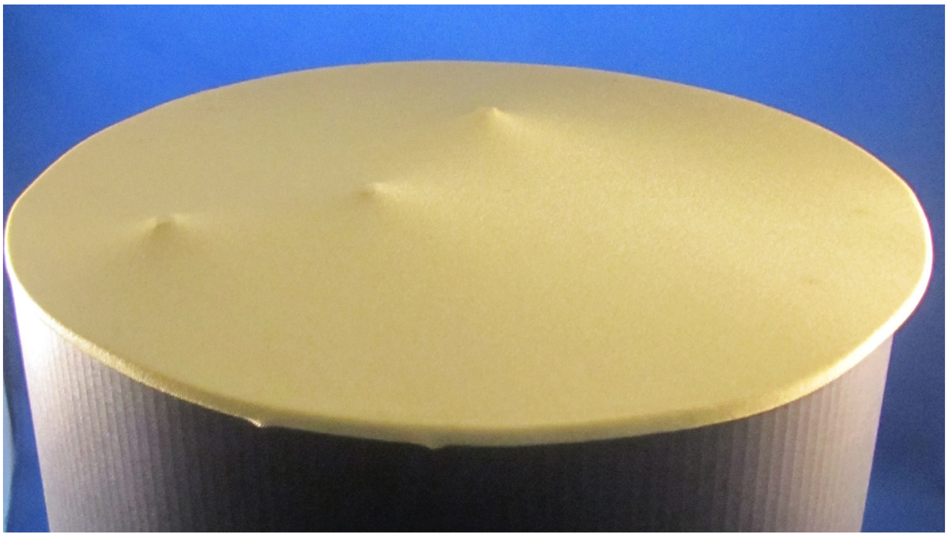


Figure 3.4 Exploring shape-change as a feedback with a low-fidelity prototype.

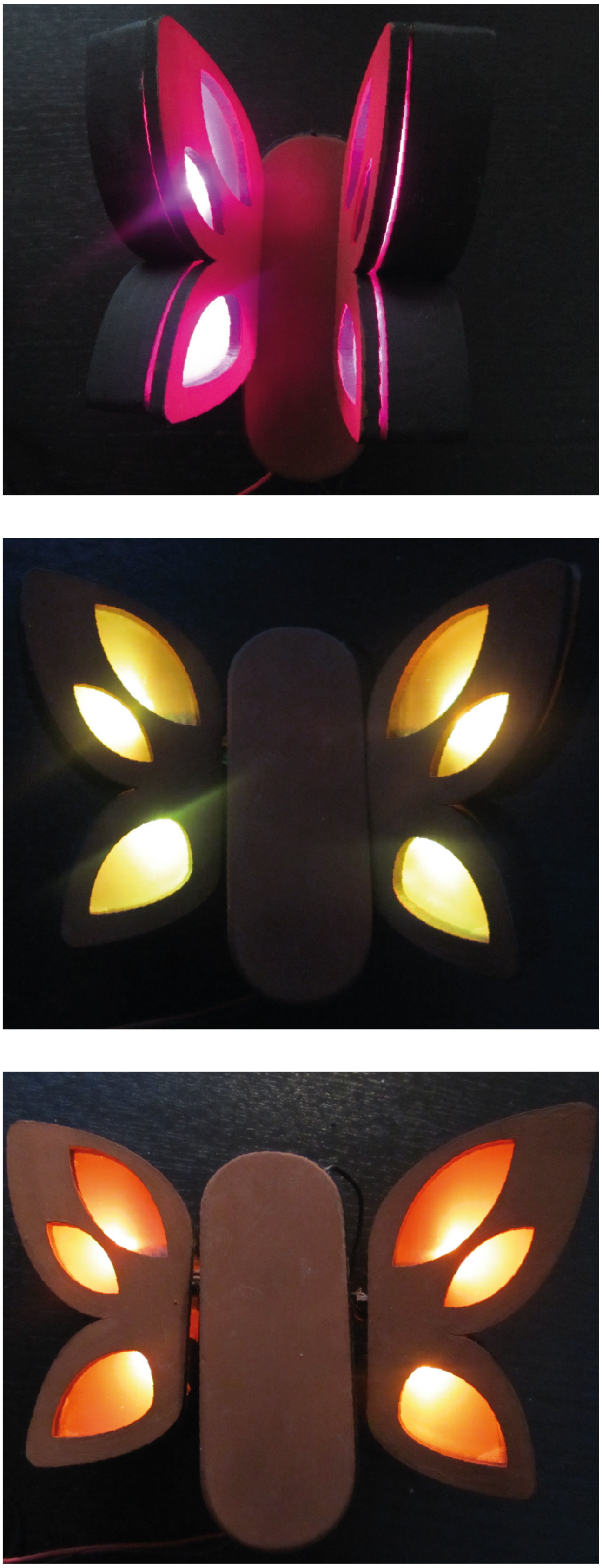


Figure 3.5 Three states of the butterfly.
Panel 3.5A: Little to no arousal measured.
Panel 3.5B: Medium amount of arousal measured.
Panel 3.5C: High amount of arousal measured.

The butterfly reference appealed as a shape for the monitoring system as well: it is fun, friendly, and appropriate for the children's age. The butterfly also enabled combining the feedback modalities of light and movement. This resulted in the following concept: When the SC signal is low, the actuator's wings are closed and colored pink, meaning little arousal is measured in the child. When the SC signal increases, the wings open and change color from pink (low arousal) to yellow (medium arousal) to orange (high arousal). Figure 3.5 shows the different states of the butterfly actuator. The colors yellow and orange were chosen because warm colors are seen as active and stimulating; therefore, these colors are corresponding with medium and high arousal (Ballast, 2002; Kaya & Epps, 2004). A calm state is usually associated with cool colors, like blue, green, or purple (Ballast, 2002; Kaya & Epps, 2004). However, an exploration proved the transition from only one cool color (representing the low arousal state) to warm colors was aesthetically unpleasant. Adding more colors to smoothen the transition made distinguishing arousal states difficult (as each color should represent one arousal state). To make the transition more aesthetically pleasing, a warm color that has a lot of blue in it (that is: a high value for blue in the RGB color code) was chosen for the low arousal state. The color chosen was pink.

Prototype development

An actuator design of the butterfly concept was created to visualize the SC signal. Three different actuators were considered to create the movement of the butterfly's wings: stepper motors, servo motors, and shape memory alloys. A shape memory alloy (SMA) is a metallic alloy that — with the addition of a temperature source or a magnetic field — can change its shape, and can return to its original shape when the temperature source or magnetic field is removed (Jani, Leary, Subic, & Gibson, 2014). The advantage of SMAs is that they are smaller and weigh less than regular actuators. However, temperature-controlled SMAs have one considerable disadvantage: the SMA heats up quickly, resulting in a quick shape change, but cools down slowly and returns slowly to its original shape. To speed this process up, a cooling source, like airflow or liquid flow, is required. This addition diminishes the advantages of SMAs being small and lightweight (Jani et al., 2014). Moreover, due to safety concerns, using a heat source so close to the child is highly undesirable. Magnetic SMAs change shapes quickly, both the change to a new form and the return to the original shape. However, the downside of magnetic SMAs is that they are very brittle, stiff, and difficult to shape (Jani et al., 2014). For these reasons, SMAs are not considered suitable for the butterfly actuator design.

Next, a stepper motor was considered. A stepper motor rotates in steps around its axis when it receives an electrical pulse. For each electrical pulse, the stepper motor rotates 15° (Elprocus, 2019). Since the SC signal is continuous, using a stepper motor to represent the child's arousal level, requires that the SC signal is translated to movement in steps of 15°. This translation may result in the loss of data and may create annoyance due to the staccato movements the butterfly will make as a result of moving in steps. The last actuator that is considered for the butterfly design is a servo motor. The servo motor has a feedback control system, wherein no current applied is a state of non-movement and current applied is a state of movement (Sawicz, 2001). The duration of applying the current determines the positioning of the servo (Sawicz, 2001). Thus, a servo can translate a continuous signal directly to movement. The range of an amplitude peak in the SC signal can be mapped to a range of durations, thereby making a range of positions of the servo — and, thus, the butterfly's wings — possible. For the butterfly actuator, a servo motor was perceived as the best solution.

For the color change of the butterfly's wings, two actuators were considered: LEDs and thermochromic ink. Thermochromic ink is ink that changes colors based on temperature (Chandler, 2012). The most iconic example of a product that uses thermochromic ink is the mood ring. The color of the ring adapts to the temperature of the skin and supposedly represents the wearer's current mood (Chandler, 2012). There are two categories of thermochromic inks: thermochromatic liquid crystals and leuco dyes. Although thermochromatic liquid crystals are highly accurate in linking a specific temperature to a particular color, their functioning will diminish with repeated exposure to UV light, water, or chemicals, and production costs are expensive (Chandler, 2012). Leuco dyes are cheaper to produce and less vulnerable to the influence of chemicals. Leuco dyes are colored with low temperatures and become translucent when heated. The primary disadvantage of leuco dyes is that their colors are not accurately mapped to temperatures (Chandler, 2012), so color change is difficult to control. However, the most important reason to not use thermochromic inks is that it requires a heat source, which is undesirable for safety reasons. LEDs offer a safer option to color the wings of the butterfly actuator. An LED is a light-emitting diode. The color of the LED is determined by the wavelength of the emitted light (LEDs Magazine, 2014). There are LEDs available that only emit one color, and RGB LEDs that emit a range of colors. RGB LEDs exist of a red, a green, and a blue LED (Random Nerd Tutorials, 2019). Due to the proximity of the three LEDs, a combination of the three colors can be perceived. By adjusting the intensity of each LED, a wide range of colors can be created (Random Nerd Tutorials, 2019).

A wooden prototype was created with the use of a laser cutter. The prototype consisted of three separate parts: the butterfly's "body" and two wings (Figure 3.6). Two servo motors — one for each wing — were responsible for the movement of the wings. The wings were connected to the butterfly's body with aluminum strips. One end of these strips was attached to the inner side of

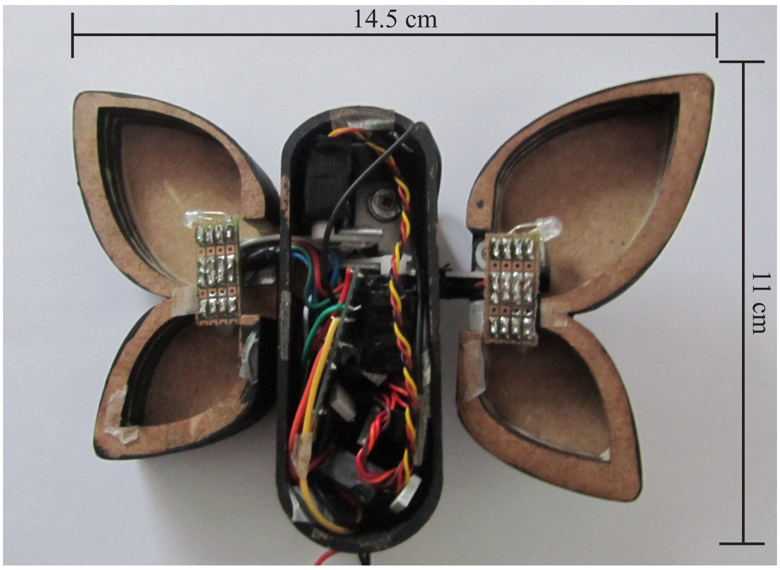


Figure 3.6 Technology in actuator design.

Figure 3.7 Simulation of the test setup.

the wing's base plate, and the other side was affixed to the arm of the servo. The color change was created with two RGB LEDs for each wing. Wires that reached over the aluminum strip connected the LEDs to an Arduino Pro Mini microcontroller located in the butterfly's body. The Arduino Pro Mini ran a program that controlled both servos and the four RGB LEDs. Since the butterfly actuator could not be directly connected to the Med–Storm pain monitor, a manual overwrite of a turning knob (potentiometer) mimicked the butterfly's behavior, simulating the same experience as if it received an SC signal (Figure 3.7).

3.3 Evaluation

The Sense monitoring system was evaluated with three parents and their children with PWS. The aim of the evaluation was twofold: (1) to validate the SC sensor's ability to reflect the child's (emotional) arousal, and (2) to evaluate the design of the butterfly actuator.

3.3.1 Participants

The participants were an 8-month old girl, a 30-month old boy, a 30-month old girl, and their mothers. The mother of dyad 1 responded to a call for participation in a closed Facebook group for parents of children with PWS (the call was placed with the administrator's consent). The mothers of dyad 2 and 3 were approached for the evaluation through one of the researchers' contacts. Both mothers had expert knowledge of the bonding process due to their professions. The mother of dyad 1 indicated experiencing mild to moderate challenges in interpreting her child's communicative signals in the first six months and the mothers of dyads 2 and 3 reported severe challenges. Only the mother of dyad 2 indicated some developmental delays in communication for her child at the time of participating (the child used signs, nodding or shaking of the head to communicate and showed fewer facial expressions than his peers). Parents could choose the location for the evaluation: their home or a lab decorated like a living room of the Eindhoven University of Technology. The mother of dyad 1 opted to visit the researchers at the university together with her 8-month old daughter with PWS and the child's grandmother. The mothers of dyad 2 and 3 choose for the home visit. All mothers provided written consent for their participation and the participation of their children prior to the evaluation. Half-way through the test with dyad 2, the child's older sister returned home from school. With the mother's consent, the sister joined the dyad in their play. Participation did not result in a reward; neither for the parents nor for their children.

3.3.2 Methods

Validating the SC sensor

To validate the sensor, the parents were requested to select separate moments of which they were certain positive (happy) and negative (unhappy) emotions were elicited in the child. The parents provided the materials for these selected moments during the test. Fifteen minutes before the start of the test, the parent attached the sticky electrodes to the child's foot as instructed in the manual of the Med–Storm pain monitor (Figure 3.2). This 15-minute time frame was intended for the child to get used to the sensor and to start the test when the child is calm. The test started with moments of negative emotions. Between each activity, was a five-minute break so that the child could calm down again. This process was repeated for the activities that elicit positive emotions.

During the tests, one researcher conducted the test and one researcher took notes of the sensor's signal on the laptop PC, the child's signals and expressions, and the activities parent and child performed. For all three tests, the role division between the researchers was maintained the same. Notes were made when the child expressed emotions or when a clear peak in the sensor signal was observed. The notes existed of the time indicated by the laptop PC, the activity performed by parent and child, events occurring in the environment, and the child's expressions and signals. After the test, the researcher who conducted the test verified the researcher's notes with her observations. For all three tests, the notes were approved.

For the older children (dyad 2 and 3), the original procedure proved unfeasible. Due to their age, they were more active and were able to walk around. Instead of separate moments of negative and positive emotions separated by a five-minute break, three different activities of at least 5 minutes were performed wherein both positive and negative emotions were either elicited by the mother (e.g., the mother introduced a different toy, or the mother ignored the signals of the child) or occurred naturally (e.g., the child falling unintentionally). Two positive situations and two negative situations of about one minute were extracted from the test data. The situations are selected based on the researcher's notes describing the time, the child's behavioral signals, and the events of the experiment.

Evaluating the butterfly actuator

The second part of the evaluation was a validation of the butterfly actuator. The child was allowed to play individually, but still in close proximity to the (grand)parent to warrant the child's safety (the electrodes on the child's foot were still attached with wires to the sensor unit). The parents were first shown the graphical representation of the Med–Storm pain monitor and received an explanation on how to interpret the graph. Next, the author provided an explanation and a demonstration of the butterfly's feedback. The author, then, attempted to simulate the butterfly's behavior based on the graphical representation of the Med–Storm pain monitor for approximately two minutes. Due to the wires limiting the child's movements and the children's increasing frustration with the wires, the simulation was kept brief. After the demonstration, parents were allowed to remove the electrodes. The evaluation was concluded with a semi-structured interview requesting the parent's opinion of the butterfly actuator system.

3.3.2 Results

Test 1

The parent of dyad 1 brought tissues for cleaning the child's hands and face and a nose spray to elicit the negative situations. The positive situations are composed of playing with the child's favorite toys, singing songs, and lifting the child in the air. In both the negative and the positive situations, the SC signal showed a steep incline at presenting the stimulus, except for the second negative situation and the third positive situation. The second negative situation (Figure 3.9) showed a steady decrease in the SC signal. Since the stimulus was a repetition of the previous stimulus (Figure 3.8) — cleaning the child's hands and face — the assumption is made that the child remembered the activity from the first situation and therefore experienced less arousal. Research from Aslin, Saffran, and Newport (1998) and Rovee-Collier (1999) indicate this quick learning is possible at the age of 8 months. Observation of the child's behavior confirmed this

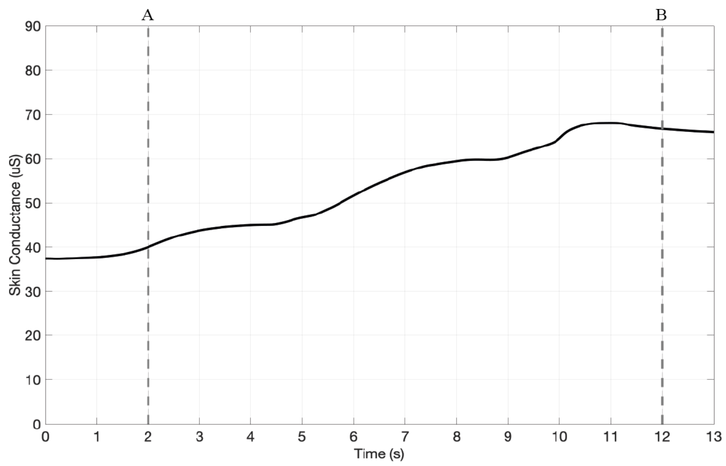


Figure 3.8 Test 1 Negative Situation 1: Cleaning child's face.
Panel 3.8A: The mother starts cleaning the child's face.
Panel 3.8B: The mother has finished cleaning the child's face.

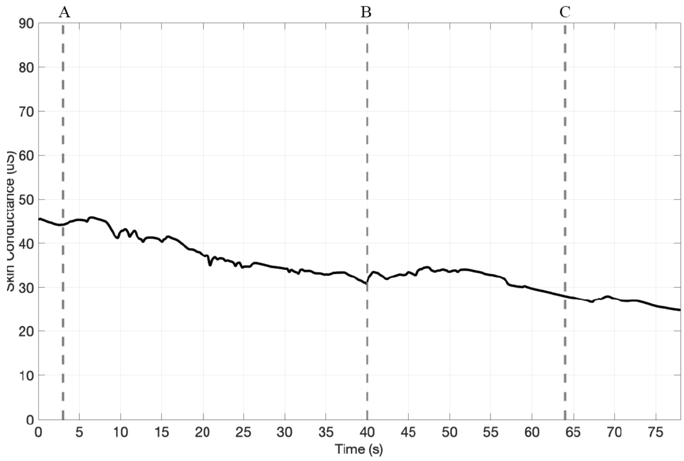


Figure 3.9 Test 1 Negative Situation 2: Cleaning child's face.
Panel 3.9A: The mother starts cleaning the child's face.
Panel 3.9B: The child starts crying.
Panel 3.9C: The mother has finished cleaning the child's face.

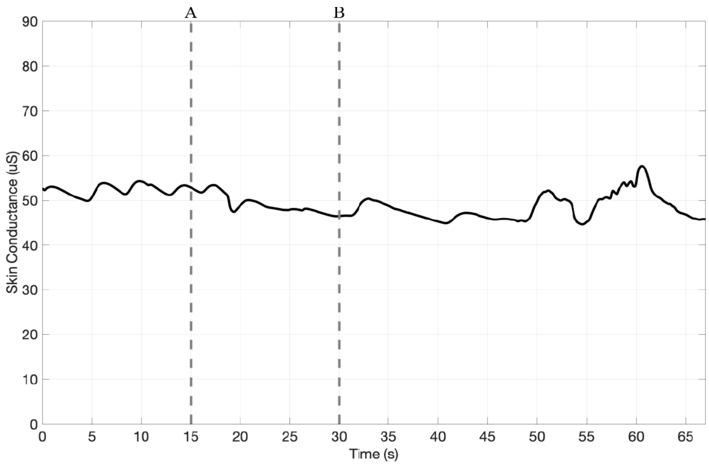


Figure 3.10 Test 1 Positive Situation 3: The grandmother makes the toy hop towards the child.
Panel 3.10A: The toy is in front of the child and the mother makes a 'boo' sound.
Panel 3.10B: The toy is in front of the child and the mother makes a 'boo' sound.

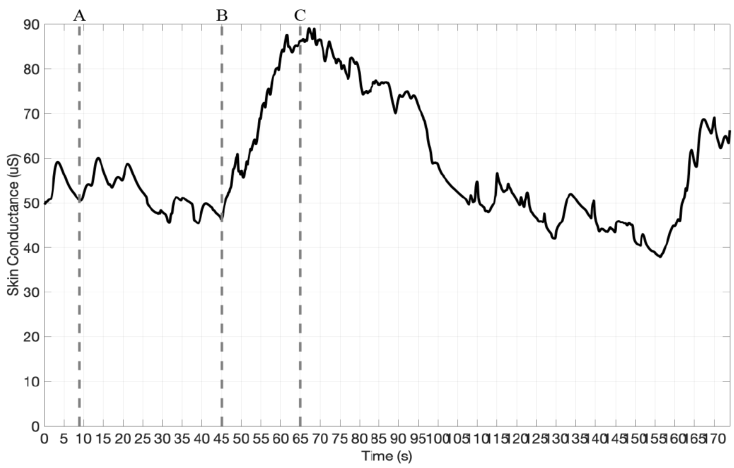


Figure 3.11 Test 1 Positive Situation 4: Lift the child in the air.
Panel 3.11A: The mother lifts the child above her head.
Panel 3.11B: The mother 'throws' the child a little distance in the air.
Panel 3.11C: The mother 'throws' the child a little distance in the air.

finding as the child made fewer protesting sounds during the repeated activity than during the first presentation of the stimulus. The third positive situation (Figure 3.10) presented a relatively flat graph in comparison to the other positive situations. This was also reflected in the child's behavior: the child stared at the parent instead of cooing and laughing in the other positive situations.

Test 2

The two negative situations selected from the second dyad's interaction were the child falling unintentionally and the mother consciously ignoring the child's behavioral signals. The positive situations were reading a book and playing together. In the moments of high arousal, both negative and positive moments, many small peaks were observed in the SC signal with a width of 1 to 3 seconds (Figures 3.12 – 3.14). The width of the peaks increased to 4 to 15 seconds

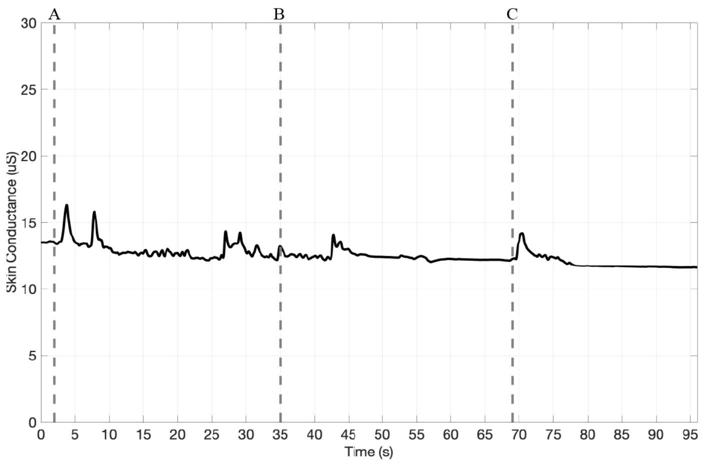


Figure 3.12 Test 2 Negative Situation 1: The child falls and is comforted by his mother.
Panel 3.12A: The child falls.
Panel 3.12B: The mother starts distracting the child with story reading.
Panel 3.12C: The child is involved in the story.

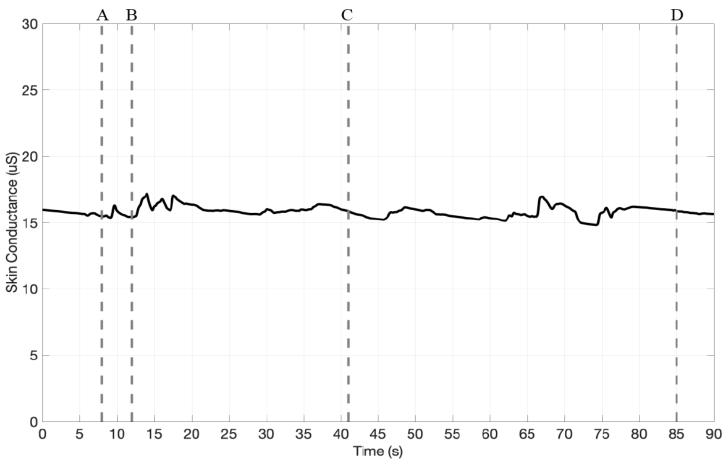


Figure 3.13 Test 2 Negative Situation 2: The mother consciously ignores the child's signals.
Panel 3.13A: Mother consciously ignore a sign from her child.
Panel 3.13B: Child starts crying.
Panel 3.13C: Mother comforts child.
Panel 3.13D: Child is involved in the play.

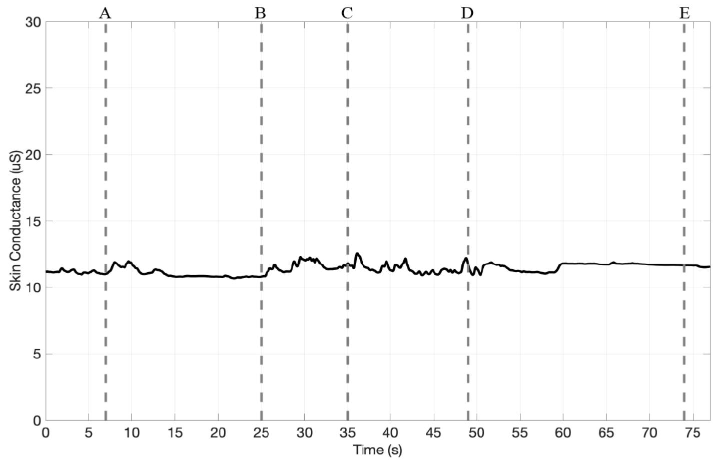


Figure 3.14 Test 2 Positive Situation 1: The mother reads a story about a cat to the child.
Panel 3.14A: Mother: "Look, a cat!"
Panel 3.14B: Mother: "The cat is running away."
Panel 3.14C: Mother: "Ah, the cat is sad."
Panel 3.14D: The child points out a fire engine.
Panel 3.14E: The story ends.

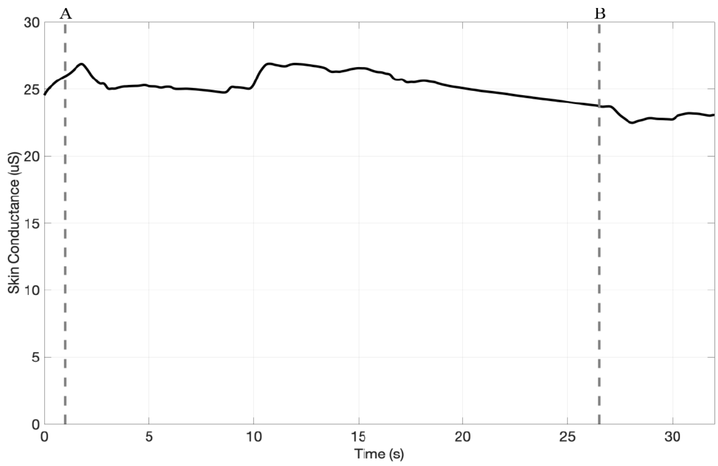


Figure 3.15 Test 2 Positive Situation 2: Mother, sister, and child are all playing together.
Panel 3.15A: The child, his sister and his mother are playing together.
Panel 3.15B: The child asks his sister to brush the doll's hair.

in moments of low arousal (e.g., the child being comforted). Also, the amplitude height of the peaks did not differ between the negative and positive situations. However, for the second positive situation (Figure 3.15), the peaks are higher than for the first positive situation. This increased amplitude was believed to be caused by the child's sister joining the play. The peaks occurring in Figure 3.14 could be matched with events in the story (e.g., turning the page or pointing out figures appearing on the page).

Test 3

The two negative situations were caused by the child's annoyance of the sensor's attachment and by receiving a warning for bad behavior. The positive situations occurred due to the mother and

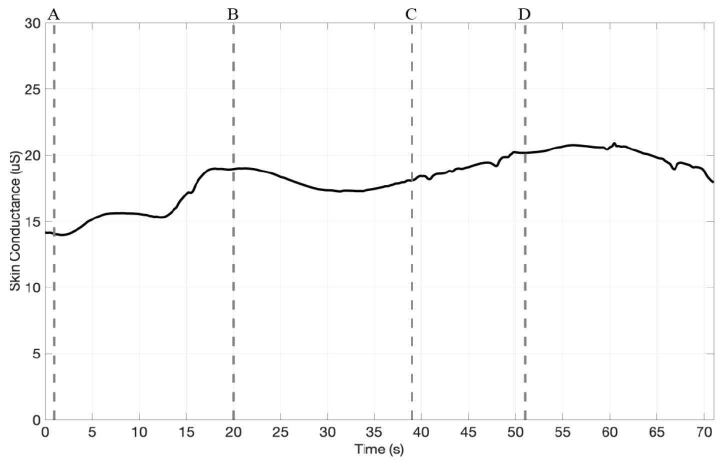


Figure 3.16 Test 3 Negative Situation 1: Child receives warning from mother.
Panel 3.16A: Mother gives child a warning.
Panel 3.16B: Silence.
Panel 3.16C: The child points out the sensor is annoying.
Panel 3.16D: The child starts crying.

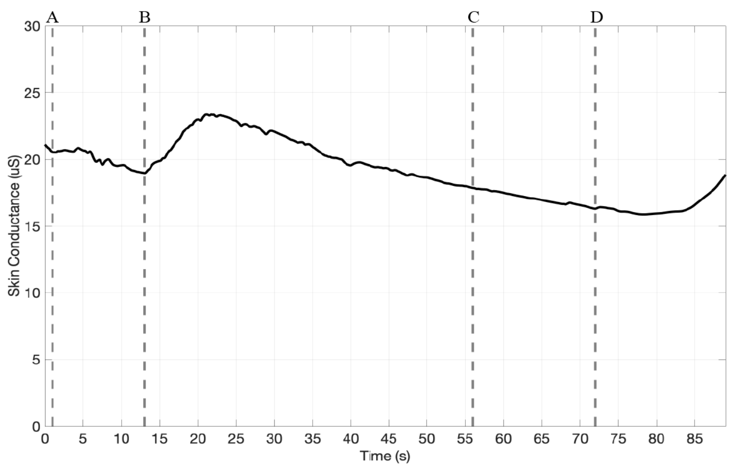


Figure 3.17 Test 3 Negative Situation 2: Child is annoyed by the sensor.
Panel 3.17A: The child points out the sensor is annoying.
Panel 3.17B: The child is distracted by mother.
Panel 3.17C: The child waves at her mother.
Panel 3.17D: The child receives a warning.

child playing together. The graphs of both negative and positive situations show an increasing trend. This trend was in line with the child's behavior changing from silence or smiling to crying or cheering. The number of peaks and the amplitude height of the peaks for the negative situations are similar to the number of peaks and the amplitude height of the peaks for the positive situations. In Figures 3.18 and 3.19, a slight increase in SC signal can be observed from the moment the child selects a card to the moment where the child discovers whether the card was the one needed to win the game.

Overall

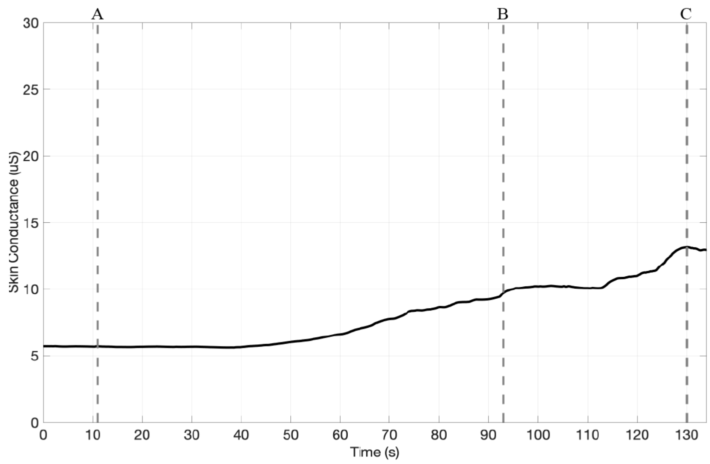


Figure 3.18 Test 3 Positive Situation 1: Mother and child play the game "Lotto."
Panel 3.18A: The child has found a card.
Panel 3.18B: The child applauds.
Panel 3.18C: The child asks to play again.

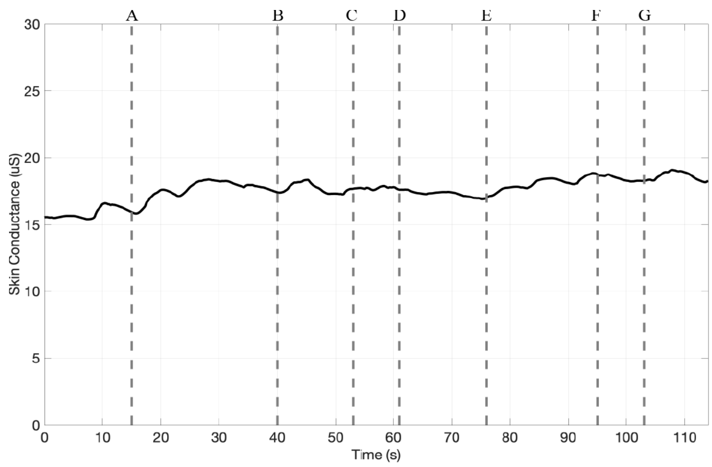


Figure 3.19 Test 3 Positive Situation 2: Mother and child play the game "Lotto."
Panel 3.19A: The child talks about her favourite drink.
Panel 3.19B: The child asks to play again.
Panel 3.19C: The child has found the right card.
Panel 3.19D: The child has found the right card.
Panel 3.19E: The child is searching for a right card.
Panel 3.19F: The child has found the right card.

All three tests have shown that the SC sensor cannot differentiate between positive and negative emotional arousal. For both the positive and negative situations, the SC signal increased upon presentation of the stimulus. However, the sensor seems to able to reflect the amount of arousal that is experienced by the child. More peaks or peaks with higher amplitudes were observed during moments of high arousal compared to low arousal moments. Finally, a link between the activities and peaks in the SC signal could be found, suggesting that the SC sensor can provide information about the child's reaction to the interaction.

Evaluation of the butterfly actuator

The evaluation of the butterfly actuator resulted in information about the most suitable moments to use the system: during feeding time, when the parents are sleeping, and during play-time. Parents indicated they missed the function of being alerted when the child is out of sight and requires attention. Parents advised adding sound to the product to trigger their attention. However, parents were positive about the actuator's ability to support social interaction. All parents indicated that they expect the system to stimulate the interaction between parent and child. One parent who experienced difficulties in recognizing the child's reaction was impressed that the system indicated the amount of arousal the child experienced. Two parents who were aware of bonding due to their professions expected the system to stimulate the bonding between parent and child.

3.4 Discussion

3.4.1 Participants

The feasibility and the design of a monitoring system that supports parents of children with PWS in their bonding and interaction process were validated with three mothers and their child with PWS. The evaluation of the system has shown positive results for the feasibility and the design of the Sense system. However, due to the small sample size, it is not possible to draw generalized conclusions. The expectation was that the Sense system is most beneficial to parents when they experience the most challenges to interpret their child's communicative signals, which occur when the child is younger than six months old. Since the prevalence of children born with PWS is low, the inclusion criteria of the participating children included an age range of 0–2 years. Even with this extended age range, two children older than two years of age were included to create a small, but more representative sample. Another limiting factor of the sample is that only mothers participated in the evaluation. Future research should attempt to include a larger sample of children younger than two years of age and also incorporate experiences and opinions from fathers (and other caregivers). Since the system could also be beneficial for parents and children with other disabilities that cause communication problems, expanding the target group might offer an opportunity for more extensive research on the system's influence on the interaction and bonding process.

3.4.2 Evaluation

The evaluation observed parents and children in their natural interaction. Due to the wired connection to the sensor and to the laptop computer, which limited the freedom to move and play for the participants, the natural interaction is likely not captured. Still, the interaction measurements were valuable in validating the system's ability to measure the child's general arousal and responses to the interaction with the parent. Even though the system did not allow for distinguishing between positive and negative events in the interaction. Future development of the monitoring system should incorporate wireless sensors to capture the natural interaction between parent and child.

3.4.3 Analysis

The SC graphs are analyzed by the author and a pediatrician of the Máxima Medical Center, Veldhoven, the Netherlands, who used the Med–Storm pain monitor in his care for premature babies in the hospital's neonatal intensive care unit. The results are not analyzed by or discussed with an expert in physiological signals, resulting in a focus on the amplitude of the peaks in the analysis. For future studies, an expert should be involved in analyzing the data to be able to retrieve more information from the data. Next to the sensor data, qualitative data was collected in a semi-structured interview. The results from the interview are analyzed and reported according to the themes introduced in the interview's questions. Recording the interview, transcribing the recording, and performing a thematic analysis of the data could have added more depth to the results.

3.4.4 Design

The iterative design process started with forming requirements for a monitoring system. These requirements were: (1) the system needs to trigger a response from parents when their child is not able to attract their attention, and (2) the system needs to support parents during the interaction with their child without interrupting the interaction process itself. The iterative process resulted in a butterfly actuator that was validated with three parents. In the interviews, parents indicated that the butterfly actuator likely would support the interaction process; however, the actuator was not able to alert parents when their child needed their attention.

Although parents observed a supporting role for the actuator in the interaction with their child, the author also observed some limitations. The butterfly actuator's dimensions (approximately 14.5 x 11 cm) were required to incorporate the technology; however, these dimensions limit the user-friendliness of the actuator design. The butterfly actuator was intended as a product that could easily be clipped on the parent's shirt sleeves or perhaps the child's shirt (similar to the pacifier cords that can be clipped on the child's shirt to prevent losing the pacifier). Instead, the actuator has to be placed close to the interaction between parents and child and requires parents to choose between observing the butterfly actuator or the child's communicative signals. Parents will also have to bring the butterfly actuator along as they go about their daily chores around the house to be able to monitor their child's arousal levels. Another down-side of the design and the dimensions of the butterfly actuator is that it could be perceived by children — especially older children — as a toy. The actuator is not designed according to safety regulations regarding children's toys, thereby causing an additional burden on parents who now have to monitor the child's safety around the butterfly actuator as well.

Another point for discussion is the butterfly actuator's representation of the SC signal through movement. This movement was derived from the movements of a butterfly's wings and the visibility of the patterns on these wings. However, the movement of the butterfly actuator's wings can be interpreted in two ways. The first interpretation conforms to the design concept: in opening the wings, more information becomes visible, which corresponds with an increased arousal level of the child. The other interpretation is that the position of the wings reflects the height of the child's arousal level. From this perspective, a high position of the wings, or earlier described as closed wings, represents high arousal. While an open or low position of the wings represents low arousal. This poses a high risk for misinterpreting the actuator's feedback and thus misinterpreting the child's arousal level.

Finally, some problems with the technology used to create the actuator design were observed. The RGB LEDs that light up the wings were positioned inside the wings for an optimal display of color. The RGB LEDs had a wired connection to the microcontroller, located in the butterfly actuator's body. The wires, therefore, moved along with the wings. This connection is fragile and not durable. Also, the servo motors posed a couple of problems. Due to the wings being directly connected to the servo, the arm of the servo had to support the weight of the wing. Although the wings are relatively lightweight, this connection caused some vibrations in the movement of the servo motor. Moreover, servo motors are not the quietest of motors. With the servo being placed inside the butterfly actuator's body, this sound was even more pronounced as the actuator's body acted as a soundbox. The vibrations in the wing's movement and the sounds from the servo made the actuator design unpleasant in its feedback.

3.5 Conclusion

The Sense system aims at stimulating the interaction between parents and their child with Prader–Willi syndrome. The system supported the interaction by measuring the child's arousal level with a skin conductance sensor and displaying the child's arousal level through a butterfly actuator design. The evaluation of the Sense system revealed that although the skin conductance sensor could not distinguish negative emotions from positive emotions, the amount of arousal and the child's reaction to the parent are measurable. Parents indicated that Sense most likely will support the interaction and bonding process between parents and their child. However, the Sense system needs further development of both the sensor and the actuator design to offer a more user-friendly system.

Preface

The previous chapter described the first iteration in the development of a monitoring system for persons with visual and severe/profound intellectual disabilities (V-S/PID). This iteration explored the design requirements for a monitoring system that supports the bonding between parents and their child with Prader–Willi syndrome (PWS). In an evaluation with three parents of children with PWS, the initial design requirements were confirmed and expanded with new requirements. The second step in the iterative process of developing a monitoring system is described in this chapter. A second iteration of the monitoring system is created to incorporate the initial and the newly found design requirements. This second iteration will be validated with three parents and their children with PWS to fine-tune the answer to research subquestion 1a "What are the design requirements for a monitoring system that is used in the daily environment of persons with V-S/PID?"

Chapter 4 Second iteration: Enlight system

4.1 Introduction

Through shared interaction, a parent and infant develop an emotional tie that nurtures the infant's development (Bicking Kinsey & Hupcey, 2013). The nature of this tie influences the expectations for close relationships an individual will develop at a later age (Rikhye et al., 2008). This emotional bond between parent and infant has been subject to many studies (Rikhye et al., 2008). It has been described from two perspectives: the tie from the infant to the parent, referred to as attachment, and the tie from the parent to the infant, described as bonding (Howe, 2006). Both perspectives indicate that the establishment of this bond is a process that requires time. Within this process, the first year of the infant's life is the most important one (Howe, 2006; Swain, Lorberbaum, Kose, & Strathearn, 2007).

The first appearance of the attachment theory is in three papers from John Bowlby in the period from 1958 to 1961 (Bowlby, 1958, 1960, 1961). Bowlby described attachment behavior as a series of "instinctual responses" that ensure closeness to an attachment figure to secure the infant's survival (Swain et al., 2007). Bowlby defined five different instinctual responses, which are clinging, following, sucking, smiling, and crying. These instinctual responses invite for care-taking behavior in the attachment figure and ensure that the child's needs are met (Swain et al., 2007). Bowlby argues that these instinctual responses develop separately and during the first year of life gradually transfer into attachment behavior (Swain et al., 2007). Repeated activation of attachment behavior forms the infant's attachment to the parent (Cataletto, Angulo, Hertz, & Whitman, 2011).

Another perspective extends Bowlby's theory to a concept of co-regulation, wherein individuals regulate their internal environment (homeostasis) as well as the internal environment of another person (Kommers, Oei, Chen, Feijs, & Bambang Oetomo, 2016). This regulation is adjusted according to cues one perceives from the other person. These cues include physiological signals, like heart rate and temperature, and physical signals, such as voice and facial expressions. The individual's response to these cues (e.g., touching) helps regulate the internal state of the other (Kommers et al., 2016). One of the cue moderators that can be used to measure the infant's attachment is oxytocin. In a study by Kommers and colleagues (2017), attachment in preterm infants is studied before and during the skin-to-skin contact with their mothers by measuring oxytocin of both infants and mothers. An increase in oxytocin during skin-to-skin contact was observed.

The theory of bonding was established by Rubin in 1967; however, this theory became renowned by the work of Klaus and Kennell in 1976 (Howe, 2006). Although not consistently used in literature, the general definition of bonding is: a strong emotional tie from the parent to the infant. The development of a close bond can be encouraged by holding the infant, signs from the infant (like crying, smiling, and visual following), positive and realistic parenting expectations, and breastfeeding. A strong tie results in more positive parenting behaviors, stimulates the cognitive and neurobehavioral development of the child, and allows the child to develop a sense of self (Howe, 2006).

The ability to develop a strong tie between parent and infant depends on the sensitivity both have for each other (Howe, 2006). The parent's sensitivity relates to the parent's ability to recognize, understand, and interpret the infant's behavior. Not being able to comprehend their infant's needs or experiencing a lack of interest in interaction from the infant, results in an increased feeling of stress for parents (Howe, 2006). Due to stress, parents become less sensitive to their infant. The infant becomes distressed when his needs are unrecognized or misunderstood (Howe, 2006). Infants, who experience stress, tend to be less responsive to external stimuli (Janssen, Schuengel, & Stolk, 2002).

Disability can be another cause for a reduced response from the infant. Infants with intellectual disabilities tend to be less reactive and less clear in their social interaction signals. The lack of clear interaction signals causes parents to experience difficulties in reading their infant's behavior and adapt to this behavior (Janssen et al., 2002). The Prader–Willi syndrome (PWS) is an example of a syndrome that causes infants to be less reactive and less clear in their social interaction signals. For a detailed explanation of PWS, please refer to Chapter 3 on page 19. To shortly recap: the majority of infants with PWS are born with severe hypotonia. The severe hypotonia in infancy causes reduced movements, resulting in the infants being inactive and sometimes almost being motionless (Reus et al., 2011). Infants with PWS often show lethargic behavior, decreased spontaneous arousal, a weak cry, feeding problems due to a poor suck reflex, and a failure to thrive (Cassidy & Driscoll, 2009; Grechi, Cammarata, Mariani, Di Candia, & Chiumello, 2012). Due to these symptoms, infants with PWS tend to request less interaction from their parents than their peers (Haig, 2008).

The presence of severe hypotonia limits the infant in expressing attachment behavior (clinging, following, sucking, smiling, and crying) and in expressing their emotions, needs, and wishes. This reduced expression of social interaction signals results in difficulties for parents to read, understand, and interpret these signals. Although the infant is limited in expressing a reaction to the parent, the infant's reaction triggers the activation of the autonomic nervous system (ANS). Through monitoring the activation of the infant's ANS, a monitoring system may provide additional cues. These additional cues might support parents in perceiving more social interaction signals and reactions from their infant and in interpreting their infant's social interaction signals.

This chapter will discuss the design and the evaluation of the Enlight system, the second iteration in the development of a monitoring system. A description of the first iteration — the Sense system — is provided in Chapter 3. Section 4.2 will describe the design of the Enlight system. This section elaborates on the design process, the design concept, and the creation of the experience prototypes. The results of the system's evaluation with three parents and their children with PWS are discussed in section 4.3. Section 4.4 provides the discussion on the evaluation results, and the conclusion can be found in section 4.5.

4.2 Design

The design process of the monitoring system's second iteration followed a Double Diamond model (Gürdür & Törngren, 2018), which is illustrated in Figure 4.1. This process started with a literature study, an interview with an expert, and a recollection of the Sense system's evaluation. The Sense system has explored the basic requirements for a monitoring system to support parents in better noticing, understanding, and responding to the communicative signals from their child with PWS. The requirements on which the Sense system is based, were: (1) the system triggers a response from parents when their child is not able to attract their attention, and (2) the system supports parents during the interaction with their child. These requirements were incorporated in a system that measured electrodermal activity, which reflects the child's general arousal level, and visualized the measured electrodermal activity in an abstract manner (through the movement and color of the actuator design).

The requirement of supporting the interaction between parents and their child is adopted as a requirement for the second iteration of the monitoring system. However, the requirement of triggering the parent's attention is excluded from further development described in this thesis. An alert to attract the parent's attention based on the measured signal depends on a threshold value for this signal. When the sensor signal exceeds this threshold value, the monitoring system will alert the parents. As the range of measured values for electrodermal activity varies per person, this threshold value will be different for each person as well. Machine learning is a method that allows for the discovery and optimization of this threshold value for each person. However, due to the author's lack of knowledge of machine learning, the decision was made to focus on the remaining design questions. Future developments of the monitoring system could explore machine learning and the design requirement of triggering the parent's attention.

Since the evaluation of the Sense system has validated that a monitoring system measuring the child's electrodermal activity is feasible, the Enlight system will be based on skin conductance

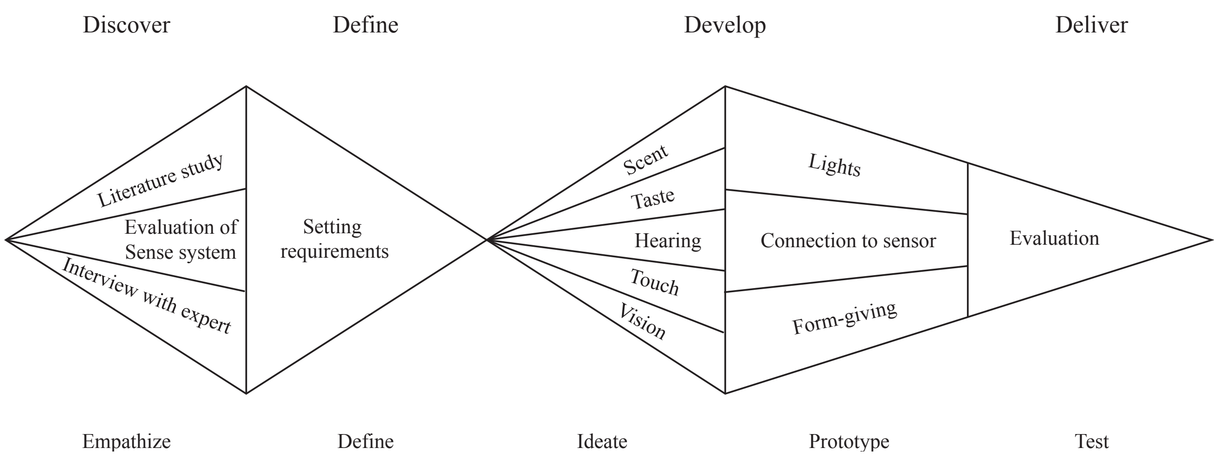


Figure 4.1 Double Diamond model of the design process of the Enlight system.

as well. The evaluation of the Sense system has also revealed more detailed requirements to incorporate in the design of the Enlight system: (1) the system should be portable and wireless in both its measurement and its feedback of the skin conductance signal, and (2) the system should be unobtrusive and comfortable. These requirements were further extended after consulting with M. Bremmer, researcher and mother of a child with PWS. The first additional requirement she provided was: the signal's feedback should not be perceivable for children with PWS as these children are prone to develop behavior to trigger the occurrence of the feedback. Furthermore, she added that the system requires an everyday look; as opposed to looking like the medical aids that parents have encountered during the many hospital visits with their child with PWS.

Based on these requirements, the Enlights system, the second iteration of the monitoring system, is created. The Enlight system consists of a sensor sock, developed by M. Croes (Eindhoven University of Technology, Eindhoven, The Netherlands), and a LED bracelet, created by the author, to communicate the skin resistance (SR) signal the sensor sock has measured.

4.2.1 Designing the measurement of physiological signal(s)

The physiological signal to be used for the second iteration was electrodermal activity (EDA). An alternative for the wired Med–Storm pain monitor, used for the first iteration, was found in the Shimmer 2R Biophysical sensor (Shimmer, Dublin, Ireland). This sensor can store the measured SR data on an SD card, or send the data via Bluetooth or WiFi to a Windows computer or an Android device. The quality of skin resistance measurement depends on the density of sweat glands, which varies for different locations in the skin. The highest density of sweat glands can be found on the sole and dorsum of the foot, the forehead, cheek, palm, and forearm (200–600 per cm^2) (Benedek & Kaernbach, 2010a,b; Ogorevc, Geršak, Novak, & Drnovšek, 2013). These are, therefore, the best locations for measuring SR. Shimmer recommends the hand or fingers as the preferred measurement location. As young children explore the world mostly with their hands, the hand or fingers were not deemed suitable as measurement location for this monitoring system. Instead, the foot was selected as measurement location.

Although the Shimmer sensor fulfilled the requirement of being portable and wireless in its measurement, it did not offer more comfort in its measurement. The standard measurement method of the Shimmer 2R Biophysical unit is gel electrodes (its attachment to the skin is comparable to an adhesive bandage). A solution was found in the use of conductive fabrics integrated into wearables. M. Croes developed a sensor sock with two integrated electrodes to replace the gel electrodes. The development of the sensor sock is described in the end report to the Prader–Willi Fonds, a Dutch foundation that supports research in the field of PWS and specifically the development of the sensor sock (Bremmer, Croes, & Sterkenburg, 2014).

4.2.2 Designing the feedback of physiological signal(s)

The process of designing the feedback of the measured SR signal started from exploring the five senses: scent, taste, hearing, touch, and vision. Each was explored for design opportunities and validated on practical implications.

Scent

The first of the five senses that is explored is scent. Scent can elicit (emotionally charged) memories (Reid, Green, Wildschut, & Sedikides, 2015), and influence emotional states and moods (Lehrner, Marwinski, Lehr, Johren, & Deecke, 2005). With the general aim of the system to support the bonding process, scent could enhance positive feelings and experiences for the parents. Scent could be used as feedback by introducing scent into the environment, alternating between scents, or increasing the intensity of the scent. The disadvantages for all these types of feedback are that the validation of the scent is highly personal (pleasant/unpleasant), scents can easily be conflicting with daily odors (e.g., from cooking), and scents become undistinguishable over time (habituation). The SR signal is continuous, while the perception of scent is momentary. Although momentary feedback could still be used to indicate when an alteration in the continuous signal occurs or when the continuous signal exceeds a certain threshold value, momentary feedback is limited in informative value. Scent as feedback is also conflicting with the design requirements since it will be perceptible to both parent and child. Given the number of disadvantages, scent is not further explored for this monitoring system.

Taste

Taste is similar in feedback opportunities as scent. Feedback can be provided by introducing a new flavor, alternating between flavors, or increasing the intensity of a flavor. Like scent, taste has the disadvantages that validation of the taste is highly personal, and that taste has a short habituation time, so distinguishing the intensity of a flavor is difficult. Furthermore, the feasibility of using taste as feedback is extremely low. Technology to change the taste in real-time with the measurement of SR is nonexistent and is unlikely to occur in the near future. Taste is, therefore, not considered a feasible feedback solution for this monitoring system.

Hearing

The major benefit of sound is that it can be perceived in the periphery of one's attention, meaning one can focus on another task, while sound provides feedback in the background (Bakker, van den Hoven, & Eggen, 2010). For parents with a child with PWS, sound would allow them to focus on the interaction with their child or on daily tasks while perceiving additional information in the background. Also, in biofeedback systems, sound is a common form of feedback through music and natural sounds (birds, water) (Yu, Funk, Hu, Wang, & Feijs, 2018). For the monitoring system, sound could provide feedback through a change in rhythm, change in pitch, change of song, change in musical instruments, or change of sounds (for example, first one hears the happy call of a bird, which then changes to the calm sounds of the sea). However, sound as feedback is conflicting with the design requirements: it is perceptible to both parent and child and may lead to the child altering his/her behavior to hear a certain sound again. For this reason, sound is not further explored for the monitoring system.

Touch

The benefit of touch is that it is personal (only the parent can perceive the feedback and not the child) and intimate (like the bond between parent and child is intimate). Feedback through

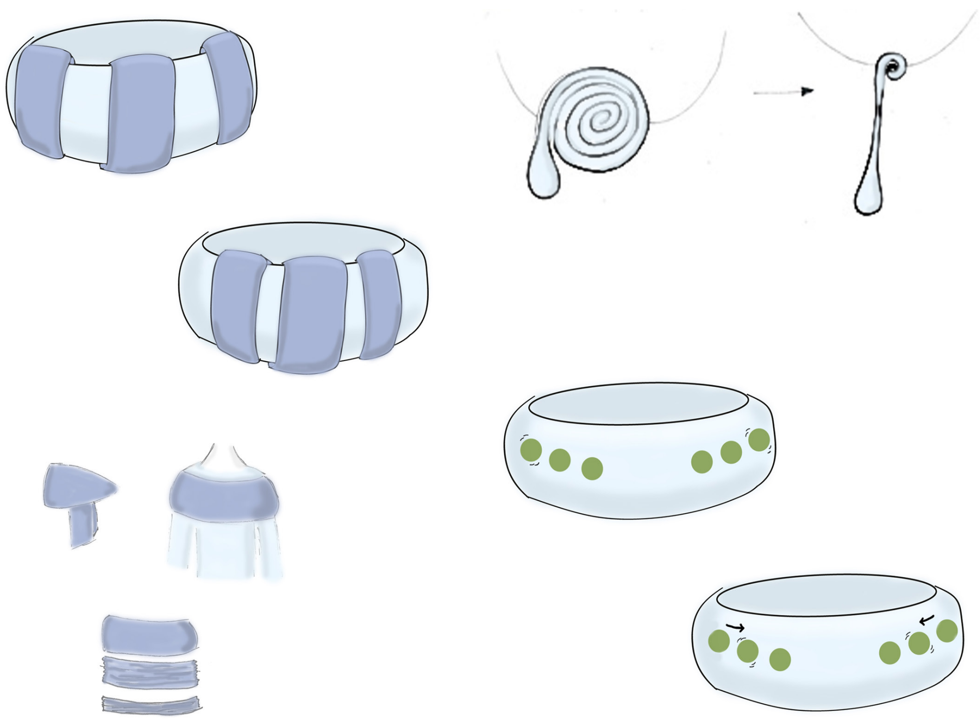


Figure 4.2 Exploration of ideas regarding the sense of touch.

touch can be in the form of shape changes (orientation, form, volume, texture, viscosity, spatiality, adding/subtracting, and permeability (Rasmussen, Pedersen, Petersen, & Hornbæk, 2012)), temperature (e.g., a wearable that can warm up or cool down), and vibration. Multiple ideas were explored: a bracelet with links that slide further apart or closer together, a shawl that changes in tightness of fit to the body, a necklace that becomes longer or shorter depending on the SR signal, or a bracelet that changes the location and the intensity of the vibrations (Figure 4.2). However, the conclusion from this exploration was that touch was not the most feasible form of feedback, because (1) it is hard to distinguish between the intensity of shape change, temperature, or vibration, and (2) the technology to enable the touch feedback is available, but at the time of development not yet robust enough for long term home-usage. Touch would be an interesting option for future developments when the required technology has evolved.

Vision

The last of the senses that is explored is vision. Vision is the most common form of feedback for biofeedback systems and occurs in the form of animations, virtual characters, displays of nature scenes, games, and ambient lights (Yu et al., 2018). For the monitoring system, feedback through vision can be provided through visuals, shape change, movement, light, and video. Multiple ideas were explored: an electronic abstract painting that changes in shapes or colors, an LED bracelet that lights up, a baby monitor that changes in color, and a shape-changing bracelet (Figure 4.3). Of all the ideas the exploration provided, the LED bracelet was deemed to be the most feasible and the clearest in its feedback; therefore, this concept was selected to develop into an experience prototype. The concept was to have the number of LEDs that light up in the bracelet reflect the infant's experienced arousal state. When the arousal level decreases, the number of LEDs that light up decreases as well. A high measurement of arousal

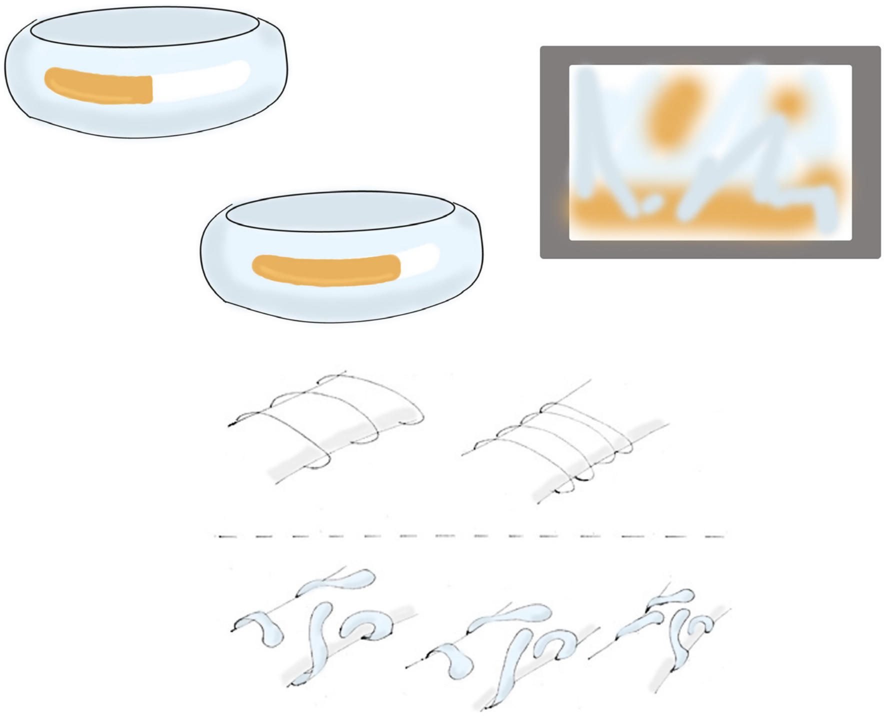


Figure 4.3 Exploration of ideas regarding the sense of vision.

ensures that a high number of LEDs light up.

4.2.3 Experience prototype

To validate the feasibility of the Enlight system, parents of infants with PWS had to be able to experience the system. Prototypes of the system's two components were created to validate the system with parents and their infants with PWS.

Sensor sock

The sensor sock, developed by M. Croes, replaced the sticky electrodes using silver-coated textile electrodes made of "Shieldex" textile. The textile is woven with silver-coated yarns that make the material feel and act like a normal fabric but conducts electricity at the same time. Two non-stretching electrodes were integrated into one sock for infants aged 6 to 12 months. Steel coated conductive yarn connects the textile electrodes on the sole of the foot to snap fasteners on the ankle, using a "zigzag" stitching pattern to maintain the stretching qualities of the sock and the conducting qualities of the yarn (Figure 4.4). The snap fastener connection is common for clinical and lab testing and was inspired by the connection of the sticky electrodes to the Shimmer 2R Biophysical module. To ensure the sock would stay in place and to add slight pressure to the textile electrodes inside the sock, so-called "Sock Ons," which ensure infants cannot take off their socks, are worn over the sensor sock.

LED bracelet

An actuator design of an LED bracelet was created to communicate the SR signal, as measured by the sensor sock, to the parents (Figure 4.5). As the bracelet was based on the SR signal,

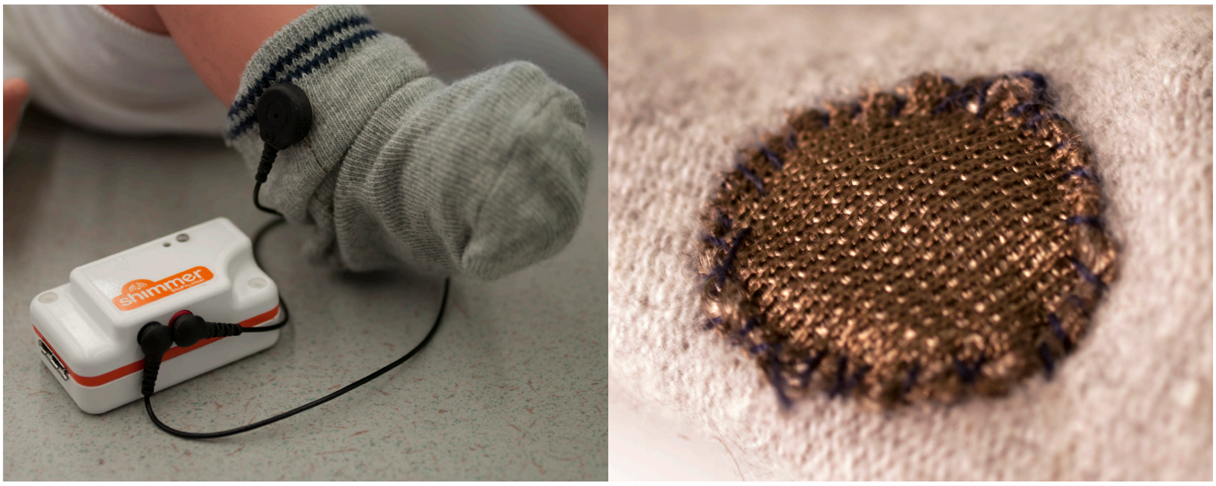


Figure 4.4 Sensor sock (photos: M. Croes).
Panel 4.4A: Sensor sock with a Shimmer 2R Biophysical module.
Panel 4.4B: Integrated fabric electrode.

the feedback deviated from the feedback intended with the concept. When the arousal level decreases, the SR signal increases, and thus the number of LEDs that light up increases. A high measurement of arousal results in a low measurement of SR and a low number of LEDs that light up.

The experience prototype of the LED bracelet received the SR sensor data via Bluetooth from a tablet PC, which is connected (via Bluetooth) to the Shimmer 2R Biophysical module attached to the sensor sock. The Shimmer module did not allow for direct Bluetooth communication with the LED bracelet, as Shimmer limited the sensor's communication to Windows and Android devices. The LED bracelet used an RN42 BlueSMiRF Silver Bluetooth module to receive the SR sensor data from the tablet PC. This Bluetooth module provides the received SR sensor data to an Arduino Pro Mini 5V microcontroller. The Arduino Pro Mini is connected to a handmade circuit board and controls nine LEDs on this circuit board.

4.3 Evaluation

The Enlight monitoring system was evaluated with three parents and their children with PWS. This evaluation aimed at validating the feasibility and usability of the monitoring system for home use. The experience prototype, consisting of the sensor sock and the LED bracelet, was presented to parents and was used during the interaction between parent and child.

4.3.1 Participants

Three mothers with their children with PWS, aged 12 to 24 months, participated in the evaluation. The participants, who had not previously participated in the Sense system's evaluation, reacted to a call in a closed Facebook group, managed by the Dutch Prader–Willi association. All mothers provided written consent for their participation and the participation of their child prior to the test. Participation did not result in a reward; neither for the parents nor for their children.

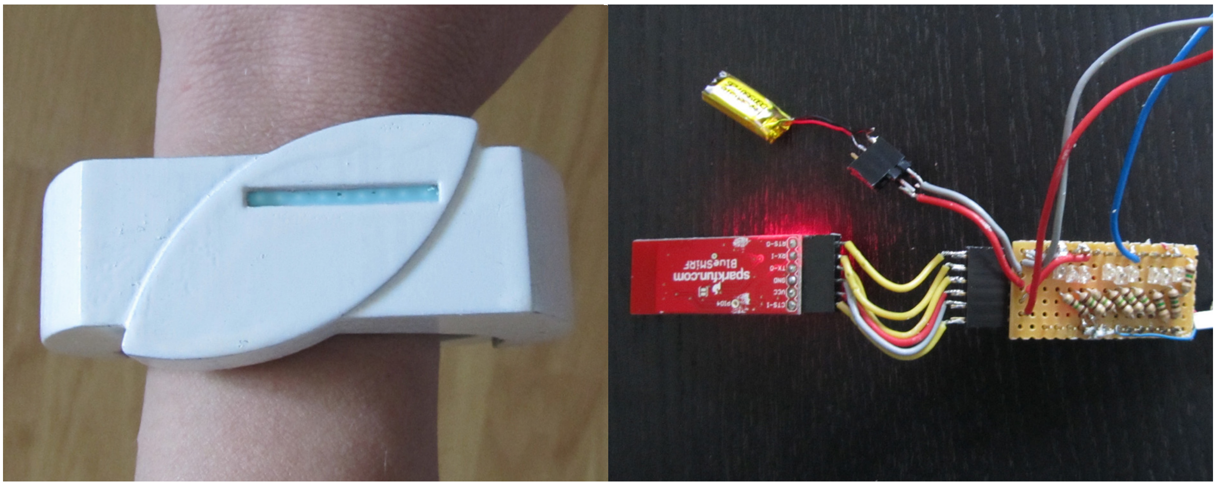


Figure 4.5 LED bracelet actuator design.
Panel 4.5A: LED bracelet.
Panel 4.5B: Components of the LED bracelet.

4.3.2 Method

The mother–child dyads took individually part in the system evaluation. Each session started with an explanation of the test procedure, an opportunity to ask questions, and the signing of the consent forms. A period of fifteen minutes preceded the test wherein the child could get used to wearing the Shimmer 2R Biophysical module and the sensor sock. During this time, a semi-structured interview was conducted with the parent to retrieve background information regarding the parent's experiences with PWS. This interview covered the following themes: the severity of their child's hypotonia and its effect on the child's behavior, the child's current behavior, the parents' perceived level of understanding of their child's behavior (in the first six months and now), the technology or other solutions parents used during the first six months, and parents' expectations of the Enlight system. After this adaptation period, the parent was requested to interact with her child for 20 minutes. The parent was instructed to allow the child to take the lead and let the child perform an activity he/she preferred to do with the parent. The test was concluded with a second semi-structured interview with the parent, following the interaction period. The second interview requested the parent's experience and opinion of the Enlight monitoring system. The themes of the second interview were: signs of discomfort from the child, parents' experience of wearing the LED bracelet, the clarity of the bracelet's feedback, the parents' use of the LED bracelet during the test, and situations the parents would like to use the Enlight system.

4.3.3 Results

All parents reported that in the first few months after birth, their child experienced severe hypotonia resulting in inactivity and for two children in almost motionless behavior. The parents also report communication difficulties because their children hardly cried and hardly produced sounds. All three mothers reported feeling insecure about interpreting their child's social interaction signals well and about understanding their child's needs in the first months after birth. All parents expressed they would like to have had access to the Enlight system during this time. However, the parents did not feel the need for the Enlight system at the child's current age, due to the significantly improved communication skills of their child. Parents indicated feeling the need to focus on their child now their child is visibly communicating with them, rather than focusing on the Enlight system.

Parents mentioned using a baby monitor to listen to the child's breathing as an indication of the child's need for attention. One parent mentioned using a baby monitor with a video function, so she could see her child at all times. One of the children required heart rate and blood saturation monitoring in the first months after birth (this monitoring was in the home environment). The parent reports being grateful for this monitoring system since it enabled her to monitor her child experiencing stress through an increased heart rate and to perceive her child's calming reaction to her efforts of calming her child down. Having experienced this monitoring system, she is highly positive about the effectiveness of the evaluated monitoring system.

After using the system for twenty minutes while interacting with their children, parents report their children behaving normally and do not report noticing any discomfort from the child about wearing the Shimmer 2R Biophysical module and the sensor sock. However, parents report having concerns about the Shimmer 2R Biophysical module's size for using it with a newborn infant. Also, the weight from the Shimmer 2R Biophysical sensor is a concern for the parents. Since newborn infants with PWS have reduced muscle strength, parents fear the sensor's weight might provide extra nuisance for the infant to use his/her legs.

Parents provide positive feedback about the LED bracelet. Although they would require a smaller size and a more unisex appearance for the bracelet, the idea behind an LED bracelet appealed to the parents. Parents report the idea of using an app for their smartphones as equally appealing. One parent, however, reports expecting the LED bracelet to be easier to use since she would not have to remind to start the application, but have the information ready at hand. Two parents indicated a high interest from their child in the lights in the LED bracelet and feeling the child wanted to play with the LED bracelet.

None of the parents reported having consciously monitored the LED bracelet for changes in the number of LEDs that light up. The parents also indicated that the LED bracelet did not attract their attention when the number of LEDs emitting light changed during the test. Two parents did occasionally look at the lights to check if the LED bracelet was still functioning. None of the mothers felt the need for the Enlight system during the interaction since they considered their children clear in their social interaction signals. One parent reported being interested in using the system when encountering new situations or unfamiliar signs from her child. One parent indicated the Enlight system might also be interesting for grandparents or daycare staff. She would be interested in a system that could travel with the child, so it becomes a tool for all caregivers to discuss the meaning of certain behavior and enable them to react similarly to that behavior. All parents indicated they would consider the Enlight monitoring system useful and relevant for the period after the child's birth since their children were very little communicative back then.

4.4 Discussion

4.4.1 Participants

The Enlight system was evaluated with three mothers and their children with PWS aged 12–24 months. Although this sample size is too small to generalize results, parents offered valuable insights for the development of a monitoring system and highlighted the need to have a comfortable, unobtrusive, and portable system for the home environment and possibly beyond the home environment (at grandparents or daycare facilities). Regarding the sample, the discussion of the Sense system (p. 36, Chapter 3) recommended the inclusion of children with PWS younger than 2 years of age. Parents of older children did not experience a need for a monitoring system as these older children had improved communication abilities. Even though the current sample fulfilled this requirement, all parents reported their children being communicative and able to express what they liked and disliked. The mothers were able to reflect on the design since they have experienced their child being non-communicative; however, to truly obtain reliable evaluation results regarding the effectiveness and the value of the Enlight system, the participation of parents with non-communicative infants is required. Another point for discussion is that only mothers participated in this study. Fathers, grandparents, and other caregivers might have different experiences with PWS and other needs for a monitoring system, which consequently influences the system's requirements. No fathers applied for participation in this research; however, future research should attempt to include the father's and other caregiver's perspectives in the study. Due to the low prevalence of children born with PWS, including children with communication impairments caused by syndromes other than PWS might improve the generalizability of the evaluation's results.

4

4.4.2 Evaluation

During the evaluation, the parents were only able to experience the prototype for twenty minutes. It is unlikely that parents encounter an unfamiliar situation in which a need for the monitoring system arises within twenty minutes of performing the child's favorite activity. However, to validate the design requirements, short exposure to the system is suitable to estimate the feasibility and the desirability of such a system. Extensive testing is required to get a more realistic experience from parents and to research the effect of a monitoring system on the interaction and the bonding process between parent and child.

4.4.3 Analysis

Although skin resistance data was collected during the evaluation, this data was not compared to observations of the child's behavior (as recorded in a video of the interaction). This analysis would have provided insight into the system's accuracy to reflect the child's arousal levels. Also, opportunities for the representation of the sensor signal might have been discovered due to a better insight into the aspects of skin resistance that provide parents with helpful information. The results reported in this chapter were collected in two semi-structured interviews and analyzed per theme covered in the interviews. More in-depth results might have been detected if the interviews had been recorded, transcribed, and analyzed with a thematical analysis.

4.4.4 Design

In the introduction several requirements for the monitoring system were formulated:
(1) the system needs to support parents during the interaction with their child;
(2) the system should be portable and wireless in both its measurement and its feedback of the physiological signal(s);
(3) the system should be unobtrusive, comfortable, and pleasant/everyday looking (as opposed to looking like a medical aid);
(4) the system's feedback should not be perceivable for children with PWS as these children are prone to develop behavior to trigger the occurrence of the feedback.

These requirements were translated to the Enlight system, consisting of a sensor sock and an LED bracelet. In the interviews, parents indicated that the Enlight system likely supports the interaction and bonding process between parents and their child with PWS. This impression is further supported by one parent's experience with a heart rate and blood saturation monitor. Although the monitoring was required for medical reasons, it also supported the mother in noticing her child's stress levels and her child's responses to their interaction.

Although both the sensor sock and the LED bracelet were portable and wireless, the LED bracelet might not be the optimal design for a portable system. In the interviews, one parent indicated an interest in sharing the monitoring system with other caregivers, like the child's grandparents or daycare staff. The sensor sock can easily travel with the child; however, sharing a bracelet between caregivers is cumbersome and passing on the bracelet to other caregivers can be easily forgotten. Having parents provide an LED bracelet for each caregiver is expensive and having each caregiver buy an LED bracelet is unrealistic, especially for the daycare staff. A portable and wireless solution might be found in an application (app) for a mobile device. All caregivers can install the app on the mobile device of their choice and can connect the mobile device to the sensor sock when the child is in their care. As mobile devices are becoming integrated into our daily lives, most people have access to a mobile device at all locations and at all times. The idea of an app was appealing to parents. Although one parent expressed concern about having to remind to start the application instead of having the information readily available with the bracelet. It is expected that when parents wonder about their child's reaction to the interaction or new situations, they will be triggered to start the app.

Parents reported no signals of discomfort or altered behavior from their child while wearing the sensor sock, confirming the sock's unobtrusiveness and comfort. Parents indicated the LED bracelet was not uncomfortable, but they treated it carefully as it concerned a prototype, which was not as robust as a finalized product. However, the LED bracelet did not fulfill all requirements as the bracelet's feedback was obtrusive and perceivable for the children. During the test, two out of three children were attracted to the lights in the LED bracelet. The children might adopt behavior that ensures all LEDs in the bracelet remain on. Since these lights reflect the infant's arousal, the infant is likely to experience stress, either positive or negative stress; therefore, this behavior is undesirable. A redesign of the bracelet is required and should consider a different feedback method or shielding the LEDs' visibility from the child.

Another point for discussion is that the feedback from the actuator design did not match the feedback from the concept. It was discovered after finishing the evaluations that the LED bracelet received skin resistance data instead of skin conductance data. As skin resistance is the opposite of skin conductance, the alteration in the measured signal (increase/decrease) is also the opposite. As parents based their reactions on the communicative signals from their child, the deviating feedback did not influence their behavior or lead to misinterpretation of the child's signals. As the idea of the design rather than the actual design was considered by parents, the validation was still valid and revealed valuable new insights for the future development of the monitoring system.

Finally, some problems with the size and form-giving of the bracelet were observed. The size of the bracelet was required to include all the technology. Although the size did not make the LED bracelet obtrusive, it looked bulky and may become obtrusive when using it for longer periods of time. Since smartwatches and activity trackers have similar features as the LED bracelet, the size can be reduced considerably by developing a tailor-made circuit board (similar to the ones of smartwatches and activity trackers), but this will also add significantly to the development costs, thereby increasing the price of the final product. The overall form-giving was specifically developed for this LED bracelet to reflect values of the parent-infant bond. The end result was a form with feminine characteristics. Although appreciated by the mothers, they expected the shape to be undesirable by men. A more general form-giving was advised.

4.5 Conclusion

The Enlight monitoring system aims at providing parents with additional cues to support them in their interaction and bonding process with their infant with PWS. This monitoring system measured the child's arousal level with a skin resistance sensor integrated into a sock and communicated the measured skin resistance to parents by means of a LED bracelet. The evaluation with parents has uncovered that although the Enlight system is portable, wireless, comfortable, and partly unobtrusive (only true for the sensor sock), the LED bracelet is not optimal to support the parent's need for a system that can travel with the child and be shared with other caregivers. The system was expected to be a valuable tool to support the parent's interaction and bonding process in the first months after the birth of their infant. However, the display of the measured physiological signal has to be developed further to enable sharing the system between caregivers and to make the feedback imperceptible for the children.

Preface

Chapter 3 and Chapter 4 have described the first and second iteration in the development of the monitoring system for persons with visual and severe/profound intellectual disabilities (V-S/PID). These iterations explored the design requirements for a monitoring system to support the bonding between parents and their child with Prader–Willi syndrome (PWS). In an evaluation with three parents of children with PWS, the initial design requirements were confirmed and expanded with new requirements. This chapter describes the third step in the iterative process of developing a monitoring system. This third iteration of the monitoring system aims at incorporating the requirements found in chapters 3 and 4. To further refine the answer to research subquestion 1a "What are the design requirements for a monitoring system that is used in the daily environment of persons with V-S/PID?", the third iteration explores the design requirements for a system used in care organizations that provide support and care to persons with V-S/PID.

Chapter 5 Third iteration: Design of the Bioresponse system

5.1 Introduction

The first iteration of the monitoring system, the Sense system (Chapter 3), and the second iteration, the Enlight system (Chapter 4), have been developed to support parents of children with Prader–Willi syndrome (PWS) in better noticing, understanding, and interpreting their child's communicative signals. The evaluations of the Sense system (page 36) and the Enlight system (page 51) have revealed that although a monitoring system would be highly valuable for parents in the first months after birth, the parents' need for a monitoring system seems to decrease when the child is one year old. As approximately 12 children with PWS are born every year (Expertisecentrum Prader–Willi syndroom, 2019), testing, producing, and marketing the monitoring system is complicated and expensive. One way to reduce the complexity and the expenses required for implementing the monitoring system is to expand the target group. Expanding the target group means that the monitoring system is adapted to and made available for other potential users with similar communicative impairments as children with PWS.

One group of potential users for the monitoring system is persons with "Ernstige Meervoudige Beperkingen (EMB)." Both children and adults with EMB experience similar communication impairments as children with PWS. Infants with PWS are lethargic, have decreased spontaneous arousal, have hypotonia — which results in reduced movement, weak suck reflex, poor cry, and less distinct emotional expressions — and a mild intellectual disability (Cassidy & Driscoll, 2009; Reus et al., 2011). EMB is a complex combination of severe intellectual, motoric, and sensory disabilities. Generally, persons with EMB have motoric disabilities causing reduced movements, are reliant on vocalizations to communicate (instead of spoken language or gestures), and have a severe or profound intellectual disability, which often causes reduced emotional expressions (Platform Ernstig Meervoudig Gehandicapt, 2019b; Adams & Oliver, 2011). This subtle communicative behavior is challenging to notice, understand, and interpret for parents of persons with EMB. There appears to be a similar need for a monitoring system from parents of persons with EMB as from parents of children with PWS.

There are approximately 10,000 persons with EMB in the Netherlands (Vereniging Gehandicaptenzorg Nederland, 2019). Not only parents have expressed a need for a monitoring system to support them in their interaction with their child with EMB, but also professional caregivers have indicated this need for support in the interaction with their clients with EMB. Approximately 90% of the persons with EMB in the Netherlands live in a home provided by an organization specialized in care and support for persons with ID and/or additional impairments

(Vereniging Gehandicaptenzorg Nederland, 2019). A monitoring system to support parents and caregivers of persons with EMB should, therefore, be usable in both the home environment and the institutional environment. This is in agreement with the requirements for a monitoring system for parents of children with PWS. In the evaluation of the Enlight system (page 52), parents expressed an interest in a system that can travel with the child and can support grandparents and daycare staff as well. Although the needs and requirements for a monitoring system for daycare facilities are not explored in the previous iterations, they are likely similar to the needs and requirements of the institutional environment for persons with EMB.

5.2 Design

The Sense system and the Enlight system have explored the design requirements for a monitoring system that supports parents in the interaction with their child with PWS in their home environment. To recap, the design requirements for this system were:

(1) the system needs to support parents during the interaction with their child;
(2) the system should be portable and wireless in both its measurement and its feedback of the physiological signal(s);
(3) the system should be unobtrusive, comfortable, and pleasant/everyday looking (as opposed to looking like a medical aid);
(4) the system's feedback should not be perceivable for children with PWS as these children are prone to develop behavior to trigger the occurrence of the feedback.

This chapter will explore a monitoring system to support professional caregivers in better noticing, understanding, and responding to the communicative signals from their clients with EMB.

5.2.1 The institutional environment

In the institutional environment, four to eight clients with EMB live in a home — later in this chapter referred to as a group home — with the support and care of professional caregivers. Clients have a shared living room and kitchen, and each client has his/her own bedroom. Depending on the intensity and nature of the support and care the clients of one group home need, one to five caregivers are present at the group home during the day. A nurse is present during the night. The care organizations provide day activity programs either in one central location or at the group home. These day activity programs are generally also available to persons with EMB who live at home with their parents. The professional caregivers at the group homes are educated to provide care and support, while the day activity caregivers have specialized knowledge of activities stimulating the client's development, attention, and interests.

Based on a visit to a group home and conversations with a caregiver and a developmental psychologist, the design requirements for the monitoring system are extended with: (1) the system should be available to multiple caregivers both during one shift and over multiple shifts, and (2) the system should be operable with a minimum number of actions to prevent adding to the high workload of the caregivers.

5.2.2 Designing the measurement of physiological signal(s)

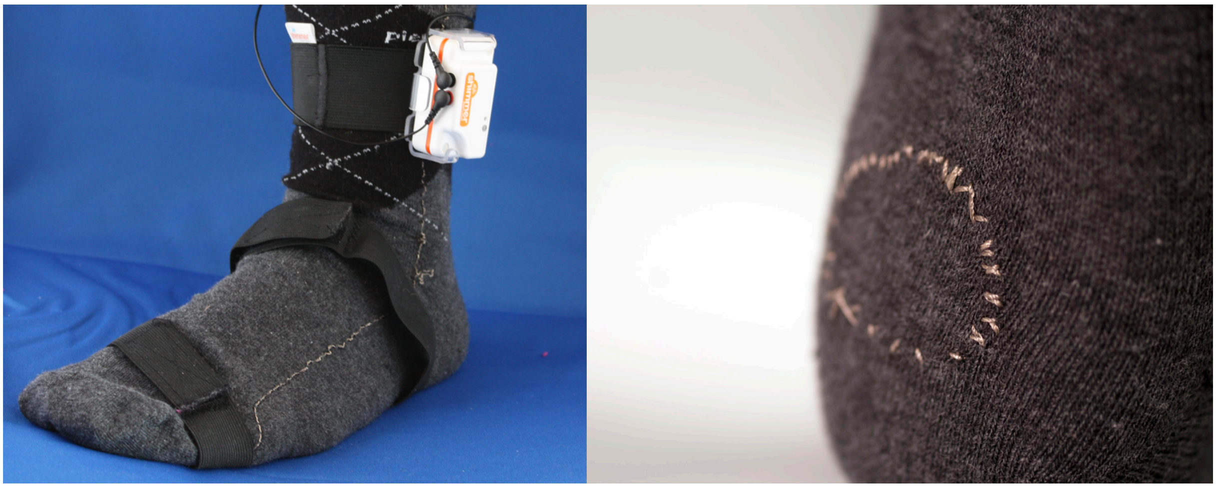


Figure 5.1 Sensor sock.
Panel 5.1A: Sensor sock with a Shimmer 2R Biophysical module.
Panel 5.1B: Integrated fabric electrode (photo: M. Croes).

In the Bioresponse system, the third iteration of the monitoring system, skin resistance (SR) is the physiological signal that is measured and visualized. The SR signal is measured by a Shimmer 2R Biophysical module (Shimmer, Dublin, Ireland) in combination with a sensor sock (Figure 5.1) developed by M. Croes (Eindhoven University of Technology, Eindhoven, the Netherlands). The development of the sensor sock is described in the end report to the Prader–Willi Fonds, a Dutch foundation that supports research in the field of PWS (Bremmer, Croes, & Sterkenburg, 2014). Two prototypes of a children's sock (age: 6–12 months) and two prototypes of an adult's sock (male sock, (Dutch) size: 43–45) were available at the start of this Ph.D. project. The number of prototypes was not sufficient for the number of participants in the studies described in part two of this thesis. Unfortunately, detailed documentation on the design of the sock was (no longer) available; therefore, new sensor socks were developed based on a close study of the prototypes developed by M. Croes. The design of these new socks is documented and described in Appendix A on page 174.

Textile electrodes integrated into the sole of the sensor sock replaced the standard gel electrodes of the Shimmer 2R Biophysical module. These electrodes are made of conductive textile and are applied with a "double running stitch." Since conductive textile is woven with silver-coated yarns, the material feels and acts like a normal fabric, but conducts electricity at the same time. The electrodes are connected to snap fasteners on the ankle, using conductive yarn. The snap fastener connection is common for clinical and lab testing and was inspired by the connection of the gel electrodes to the Shimmer 2R Biophysical module. The conductive yarn is applied with a "stoating stitch" to the outside of the sensor sock. The "stoating stitch" ensures that the conductive yarn does not make skin contact, thereby preventing noise on the SR measurement. On the advice of Statex (Statex, Bremen, Germany), the company that supplied the conductive materials, Shieldex® Technik-tex P130 was used for the textile electrodes and Shieldex® 117/17dtex 2ply HC was the conductive yarn used to connect the electrodes with the snap fasteners.

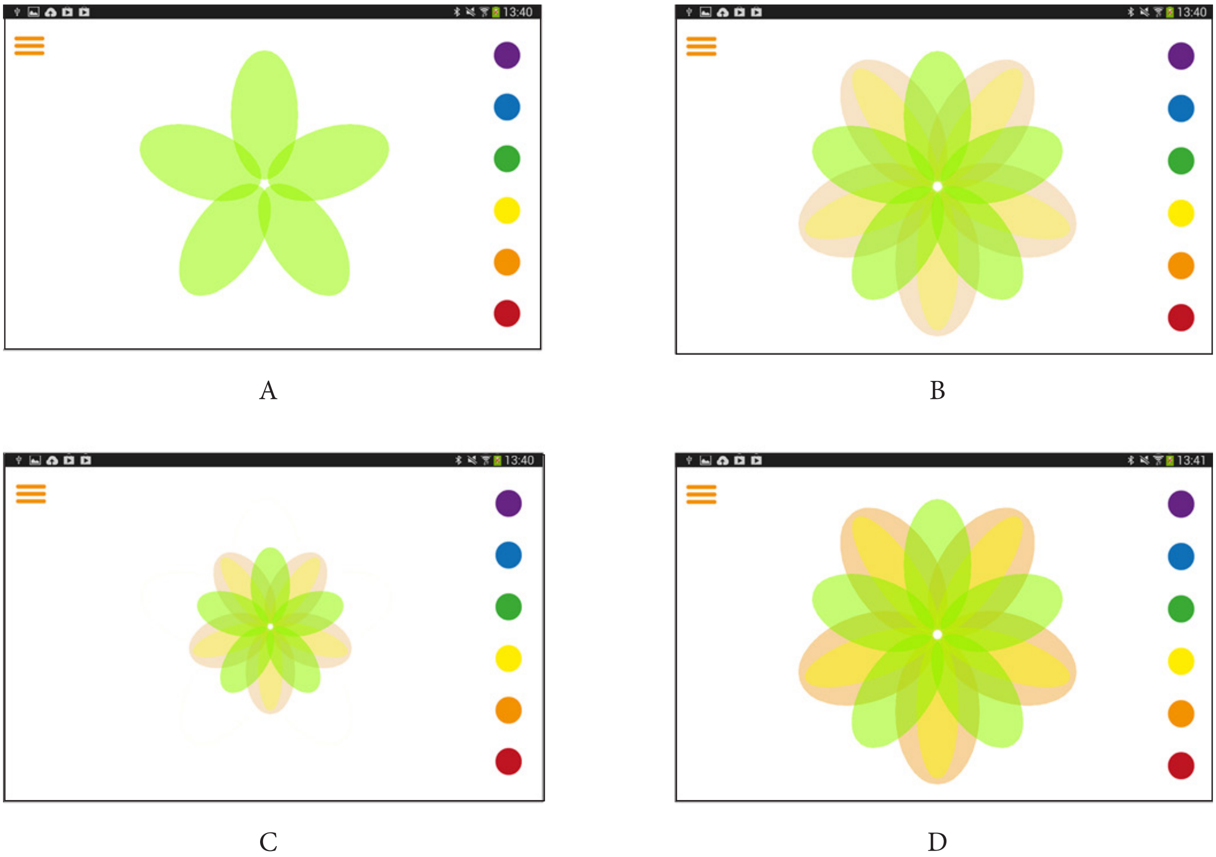


Figure 5.2 Flower app — Visualization of the skin resistance signal in the form of a flower.
Panel 5.2A: low arousal, low reaction to stimuli;
Panel 5.2B: low arousal, medium reaction to stimuli;
Panel 5.2C: high arousal, medium reaction to stimuli;
Panel 5.2D: low arousal, high reaction to stimuli.

5.2.3 Designing the feedback of physiological signal(s)

The discussion of the Enlight system (page 52) concluded that a tangible product to provide feedback of the measured physiological signal is unsuitable for institutional environments. Tangible products become a nuisance when sharing them with multiple users and locations. The use of an application (app) was suggested as a solution. All caregivers can install the app on the mobile device of their choice and can connect the mobile device to the sensor sock when the client is in their care. For the Bioresponse system, a tailor-made Android application, called the Flower app, was developed by M. Croes and L. Vork (Eindhoven University of Technology, Eindhoven, the Netherlands). The development of the Flower app is described in the end report to the Prader–Willi Fonds (Bremmer et al., 2014). This app receives the SR signal via Bluetooth from the Shimmer 2R Biophysical module. The SR signal is visualized in the shape of a flower. Increasing general arousal levels result in a decrease in the SR signal and a decrease in the flower's size. A decrease in general arousal level generates an increasing SR signal and an increase in the flower's size (Figure 5.2). The client's responses to stimuli in the environment, such as hearing one's name or music in the background, are shown in the SR signal as small peaks. An increasing number of peaks detected in the SR signal is visualized through the appearance of additional (orange) flower petals (Figure 5.2). Next to the flower, six

Figure 5.3 Pressure (displayed through the arrows) on the two integrated fabric electrodes in the sensor sock while walking.

colored buttons are displayed. Caregivers can use these buttons to record their observations of the client's behavior. Each color (meaning each button) represents an arousal state with purple standing for "low alertness"; blue for "understimulated"; green for "relaxed"; yellow for "a little tense"; orange for "tense"; and red for "stressed". The colors of these buttons match the "signaling list" (in Dutch: signaleringsplan), a tool to support the interpretation of the client's behavior. For the studies discussed in this thesis, P. Peters (Eindhoven University of Technology, Eindhoven, the Netherlands) updated the app to the newest Android version at the time and adapted the Flower app to filter outliers from the visualization and to display text with the six colored buttons.

5.2.4 Reflection on the Bioresponse system's design

The sensor sock was developed to offer a more comfortable solution for continuous electrodermal activity measurements than the standard gel electrodes provide. Although the sock has generally been more comfortable than the standard gel electrodes, there are two main problems with the sock remaining. The first problem is the standard strap that Shimmer provides for its sensors. Some clients with EMB have shown resistance against wearing this strap. Secondly, the design of the sensor sock has excluded clients with EMB who were unable to remain seated for longer periods of time. Due to the location of the fabric electrodes — at the metatarsal (just under the toes) and the heel of the foot — the pressure on the fabric electrodes becomes unequal when walking (Figure 5.3). This unequal pressure results in amplitude changes in the electrodermal measurements and changes in the flower's size, which are unrelated to changes in arousal. Thus, the feedback from the flower becomes unusable.

To be able to use the Bioresponse system, caregivers need to exchange the client's sock for the sensor sock, switch on the sensor, place the sensor in the holder, strap the holder around the client's ankle, and connect the sensor with the sensor sock. Then, to see the feedback of the flower in the Flower app, caregivers need to go through six more steps: (1) switch on the tablet, (2) start the app, (3) open the menu, (4) click the "connect to sensor" button, (5) open the menu (a second time), and (6) click the "start program" button. The number of required steps is not

Figure 5.4 Concept design for sensor sock with a small pocket that holds the Shimmer sensor.

in accordance with the design requirement "the system should be operable with a minimum number of actions," and could likely be reduced. Especially, the number of steps needed to operate the Flower app could be reduced to three steps: (1) switch on the tablet, (2) start the app, (3) click the "start program" button.

Next to the number of steps required to operate the app, caregivers experienced several problems with the app. Caregivers indicated that it was difficult to detect changes in the flower's size when they were focused on their task and not observing the app actively for a few minutes. They wanted some references to interpret the size of the flower. The meaning of the flower itself (the difference between flower petals and the color of the flower in relation to the buttons) was also unclear at moments. Caregivers would benefit from a more intuitive visualization of the skin resistance signal. A more technical problem was the occasional difficulty to make connection with the Shimmer 2R Biophysical module, which added more steps before the system was ready for usage.

5.3 Redesign

5.3.1 The sensor sock

The reflection on the design of the sensor sock has revealed several problems with the current design. The first problem is the standard strap that Shimmer provides for its sensors. Two clients dropped out of the randomized multiple baseline study (described in chapters 10, 11, and 12) because they showed resistance against wearing this strap. A possible solution for this problem could be the addition of a little pocket to the sensor sock. The sensor could be inserted in this pocket and the wires can travel from inside the pocket to the strap fasteners (see Figure 5.4). Exploration of this solution is needed to discover whether attaching the Shimmer sensor without the strap is sufficient for the clients to accept the sensor sock or whether the sensor's weight and the hardness of the material are stressing the clients. Another potential downside of this solution is that this sock design cannot be used with orthopedic shoes because the pocket's location would be inside the shoe. Due to the tight fit of orthopedic shoes, the sensor being inside the shoe would be uncomfortable and likely even painful. Time limitations in this project

Figure 5.5 Concept for the sensor sock to allow for the client to walk around during measurements.
Panel 5.5A: Location of the two integrated fabric electrodes in the current sensor sock while walking.
Panel 5.5B: Location of the two integrated fabric electrodes in the concept sensor sock while walking.

did not allow for the exploration of this solution.

The second problem was that the placement of the electrodes within the sock required the client to remain seated. A possible solution to allow the client to walk around while wearing the sock is to place the electrodes on the ankle (see Figure 5.5). In a study by van Dooren, de Vries, and Janssen (2012), sixteen skin conductance measurement locations are compared, including the ankle. They have shown that although it is not as accurate as measurement on the palm of the hands or sole of the foot, it gives a reasonable result. Explorations with measurements on the ankle are required to validate this measurement location is suitable; both while remaining seated and while walking around. However, time for these validations was not available.

In the process of creating sensor socks for the pilot studies and the randomized multiple baseline study (part II of this thesis), the application of the electrodes, connecting wires, and strap fasteners aimed to resemble the prototype as close as possible. In the redesign of the sock, the best way to apply those components to the sensor sock was explored. The exploration started with the application of the fabric electrodes. Twenty-one hand stitches (Figure 5.6) were compared on comfort, aesthetics (both on the inside and the outside of the sock), the speed of application, and the security of the application. Each category could be scored: positive (+), neutral (0), or negative (-) (Table 5.1). This scoring was done by the author. A stitch rated positively on comfort when it hardly could be felt, neutral when it could be felt a little, and negative when it could be felt a lot. Aesthetics were rated positively when the stitch looked neat or could not be seen, neutral when the stitching was uneven, and negative when the stitching looked messy. If the application of the stitch was quick, it was labeled positive. If the application was average, the label was neutral. The label was negative when the application was laborious. The security of the application of the stitch was rated positively when all edges were secured, neutral when most of the electrode's edge was secured, and negative when the edge was not secured. Comfort was considered the most important criterium, and only stitches that scored positive on this criterium were considered for the redesign. Six stitches scored positive on comfort: the running

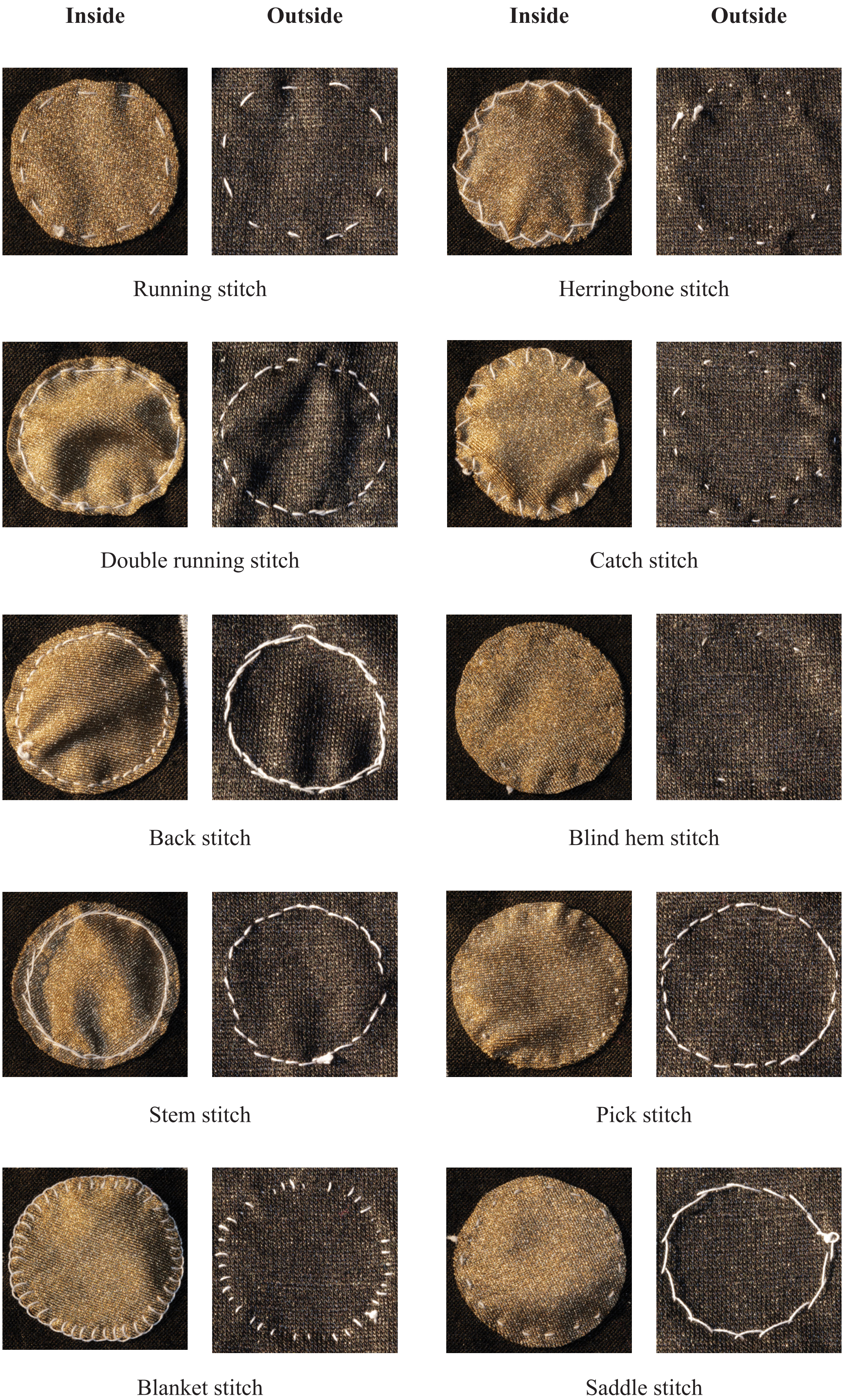


Figure 5.6 Exploration of stitches. An overview of stitches that can be potentially used for attaching the fabric electrodes to the regular sock.

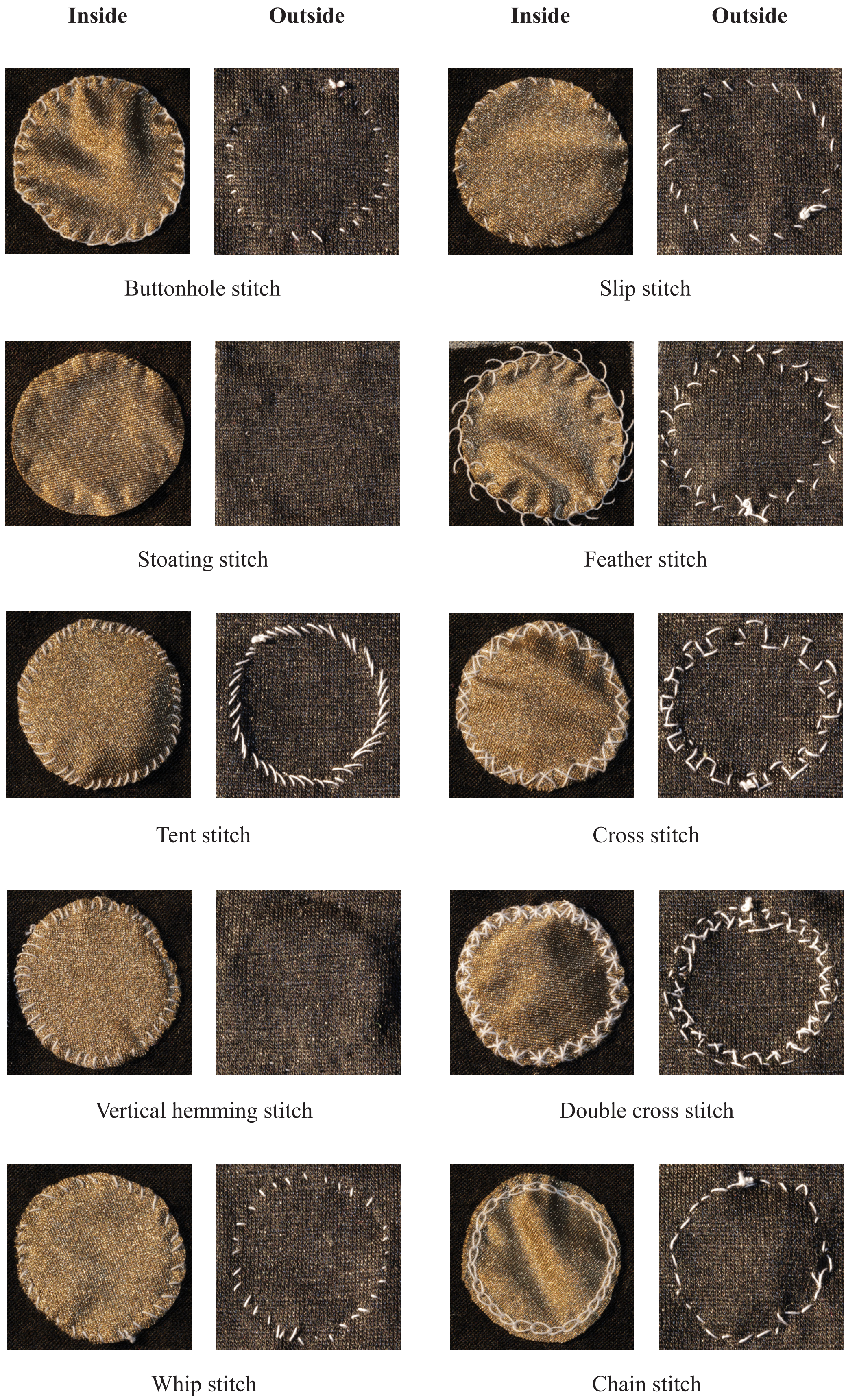
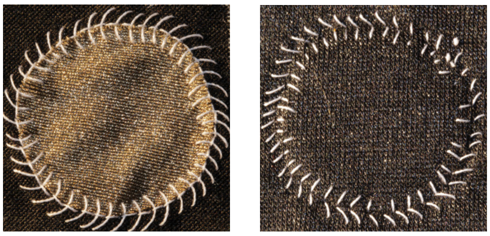


Figure 5.6 Continued Exploration of stitches. An overview of stitches that can be potentially used for attaching the fabric electrodes to the regular sock.

Inside **Outside**



Fern stitch

Figure 5.6 Continued Exploration of stitches. An overview of stitches that can be potentially used for attaching the fabric electrodes to the regular sock.

stitch, the double running stitch, the herringbone stitch, the catch stitch, the blind hem stitch, and the pick stitch. To be included in the redesign, the stitches had to score positive or neutral on the other criteria. The herringbone stitch was the only stitch that scored positive or neutral on the remaining criteria. Furthermore, two types of wires were compared for application of the electrodes: conductive yarn (Shieldex® 117/17dtex 2ply HC) and regular yarn (Gütermann, 100% polyester, 220 yds/vgs). The regular yarn was thinner, softer, and woven more tightly

Stitches	**Comfort**	**Aesthetics**		**Application**	
		Inside sock	Outside sock	Speed	Security
1. Running stitch	+	0	0	+	-
2. Double running stitch	+	+	+	+	-
3. Back stitch	0	+	-	+	-
4. Stem stitch	0	0	+	0	-
5. Blanket stitch	-	+	+	0	+
6. Buttonhole stitch	-	+	+	0	+
7. Herringbone stitch	+	+	+	0	0
8. Catch stitch	+	-	+	+	0
9. Blind hem stitch	+	0	+	+	-
10. Pick stitch	+	0	+	0	-
11. Saddle stitch	0	0	-	+	-
12. Slip stitch	0	0	+	0	0
13. Stoating stitch	+	0	+	0	-
14. Tent stitch	-	+	0	0	0
15. Vertical hemming stitch	0	+	+	0	0
16. Whip stitch	0	+	+	0	0
17. Fern stitch	-	+	+	-	+
18. Feather stitch	0	+	0	-	+
19. Cross stitch	0	+	0	-	+
20. Double cross stitch	-	+	0	-	+
21. Chain stitch	0	+	0	-	-

Table 5.1 Comparison of the twenty-one hand stitches on their comfort, aesthetics and application.

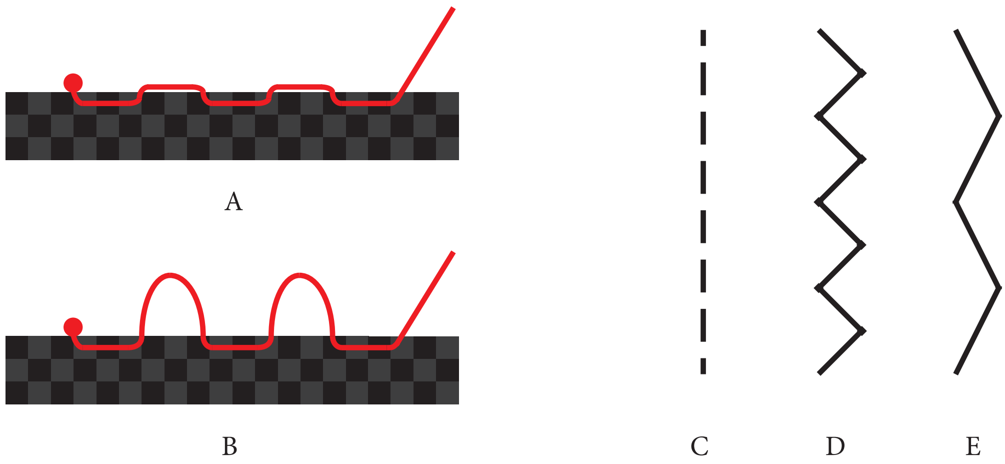


Figure 5.7 Exploration of stoating stitch patterns for the application of the connecting wires.
Panel 5.7A: Side view of a normal stoating stitch.
Panel 5.7B: Side view of a stoating stitch with give.
Panel 5.7C: Top view of a straight pattern.
Panel 5.7D: Top view of a narrow zigzag pattern.
Panel 5.7E: Top view of a wide zigzag pattern.

than the conductive yarn. Due to those qualities, the regular yarn was easier to apply, and the stitching was less noticeable and more comfortable. A herringbone stitch using regular yarn is, therefore, considered the best stitch for applying the fabric electrodes to the sensor sock.

The fabric electrodes are connected to the Shimmer 2R Biophysical sensor through conductive yarn and snap fasteners. The conductive yarn has to be applied to the outside of the sensor sock only. If the yarn appears on the inside of the sock, it connects directly to the skin; thereby, potentially registering SR and creating noise in the SR signal. Out of the twenty-one stitches considered for the application of the fabric electrodes, the stoating stitch is the only stitch that does not go through the fabric but stays on the outside of the sock only. Another important aspect of the conductive yarn's application is that the stretching quality of the sock remains intact. Six different application patterns (Figure 5.7) with the stoating stitch are compared on the distance the fabric can stretch: a straight stitch (1.5 cm), a straight stitch with give (5.5 cm), a narrow zigzag (4.5 cm), a narrow zigzag with give (8 cm), a wide zigzag (2 cm), and a wide zigzag with give (5.5 cm). A stoating stitch in a narrow zigzag with give pattern is the best solution for applying the connecting wires to the sensor sock.

5.3.2 The Flower app

The reflection on the design of the Flower app has revealed that the most important improvement to the design is to reduce the number of actions caregivers have to take to operate the app. To see the feedback of the flower in the Flower app, caregivers need to go through six steps: (1) switch on the tablet, (2) start the app, (3) open the menu, (4) click the "connect to sensor" button, (5) open the menu (a second time), and (6) click the "start program" button. In the redesign of the Flower app, made by P. Peters and the author (Eindhoven University of Technology, Eindhoven, the Netherlands), this number of steps is reduced to (1) switch on the tablet, (2) start the app, and (3) click on the "start" button (Figure 5.8A). The second main improvement made to the app is that the flower visualization reflects skin conductance (SC) instead of skin resistance (SR). Having a flower visualize SR means that the size of the flower will decrease when the arousal increases. This feedback is counter-intuitive. However, having a flower that reflects SC results in an increasing flower size when the arousal increases.

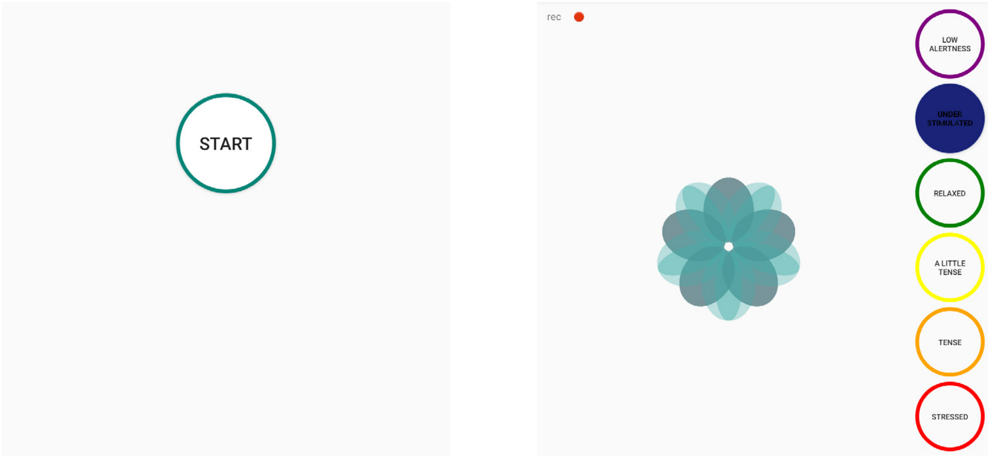
Other changes included a new look for the buttons caregiver can use to indicate their behavioral observations. Before, the buttons had an initial state of a filled circle with text next to it. Upon selection, the button displayed a thin circle around the button. When using the app at a small distance, it was hard to notice when the button was selected. For the redesign, the button is a circle with the text inside the button. When selected the button is filled with color, so the selection is easily visible (Figure 5.8B). The color of the flower has also changed. Feedback from caregivers indicated that the colors resembled the button colors too closely; therefore, it was easy to interpret the color of the flower as an indication of the feeling state that is connected to the button with the same color. The flower in the redesign uses two shades of blue that do not closely resemble the blue used for one of the buttons (Figure 5.8B). Blue was chosen because it has a less strong association with feeling states than other colors (e.g., red meaning angry, yellow representing happiness). The last change in the redesign is the addition of a record indication. In the randomized multiple baseline study (described in chapters 10, 11, and 12), the Flower app had two modes: (1) the feedback (thus the flower) is visible and (2) the feedback is not visible. In the second mode, it was hard to notice whether the app was still recording data. To provide reassurance that data is being collected, a red blinking dot next to the text "rec" is displayed in both modes (Figure 5.8B).

5.3.3 Reflection on the redesign of the Bioresponse system

In the redesign, some minor and immediate problems with the design of the Bioresponse system were resolved. However, some major issues are as yet unresolved, due to time constraints. For the sensor sock, the applications of the components have been explored and the best application is now defined. The fabric electrodes can best be applied to the sock using regular yarn and a herringbone stitch. A stoating stitch applied in a narrow zigzag pattern with give is best used for the application of the connecting wires. However, the problems of clients resisting the sensor strap and not being able to use the sensor sock while walking are not resolved. Solutions have been suggested, but are as yet unexplored. Other solutions, like using a different garment (e.g., a shirt), need to be explored as well to find the best product to measure the physiological signals with clients with EMB. For the Flower app, a new, more user-friendly app was designed. The number of actions to operate the app is significantly reduced, button states are more clear, and the color pallet has been adapted to prevent confusion. Although the visualization has become more intuitive with the flower reflecting SC instead of SR, the visualization with two colors in flower petals and their different meaning has not changed. Future explorations to discover a more intuitive design are needed. Also, the connectivity problems have — despite thorough investigation — not yet been resolved.

5.4 Conclusion

The Bioresponse system aims at providing professional caregivers with additional cues to



A B

Figure 5.8 Screenshots from the redesigned Flower app.
Panel 5.8A: Start screen of the new Flower app design.
Panel 5.5B: The flower visualization and the buttons in the new Flower app design.

support them in their interaction with their clients with EMB. This monitoring system measured the client's arousal level with a skin resistance sensor integrated into a sock and communicated the measured skin resistance to caregivers by means of an app. Although the Bioresponse system is more comfortable to wear than standard gel electrodes, the system is not yet easy to use nor usable in all situations and with all clients. The Bioresponse system needs further development of both the sensor sock and the Flower app to offer a more user-friendly system suitable for the institutional environment.

Preface

Through an iterative design process, the previous chapters have addressed the research subquestions 1a “What are the design requirements for a monitoring system that is used in the daily environment of persons with visual and severe/profound intellectual disabilities (V-S/PID)?” and 1b “Can technologies, developed to measure (emotional) arousal for persons without disabilities, also measure (emotional) arousal for persons with V-S/PID?” The aim of this chapter is to address the research subquestions 1c “What are (the requirements for) the components that compose a monitoring system for persons with V-S/PID?” and 1d “What are the requirements for marketing a monitoring system for persons with V-S/PID?” First, a set of design guidelines — that is based on a reflection of the iterative design process — are provided. To conclude the first part of this thesis, the future of the Bioresponse system is considered and a set of guidelines for marketing a monitoring system is described.

Section 7.2 of this chapter is based on a pre-print of: Frederiks, K., Sterkenburg, S., Lavner, Y., Cohen, R., Ruinskiy, D., Verbeke, W. & IJzerman, H. (PsyArchiv). Mobile Social Physiology as the Future of Relationship Research and Therapy: Presentation of the Bio-App for Bonding (BAB). https://psyarxiv.com/xr8ma

Chapter 6 Retrospect and outlook on the design of a monitoring system

6.1 Introduction

In design, there are roughly two approaches: (1) design for innovation and (2) design for research. In innovation, the product is the end goal; while in research, the product is the means to gain knowledge. Each approach has its own process. The model of Product Innovation is used here to illustrate the process of *design for innovation*. Product Innovation starts with Strategy Formulation. In this phase, a company will formulate its goals — what products does the company want to produce now and in the future? — and its strategies to accomplish these goals. External research (what are the consumer needs?) and internal investigation (what are the company's strengths and weaknesses?) are combined into search areas. Search areas are evaluated using among others user studies, expert feedback, and patent checks. From these search areas product ideas are generated. In the next phase, Design Brief Formulation, one search area is selected and described in more detail. The third phase is Product Development, in which product ideas are iteratively transformed into detailed plans for the product, the production, and the sale. The last phase is Product Launch and Use, which includes the actual production, marketing, distribution, sales, and use of the product (Buijs, 2003; van Boeijen & Daalhuizen, 2010).

In *design for research*, the product is used as a means to better understand the context or the problem statement, to validate findings, and to develop theories or methods (Koskinen, Zimmerman, Binder, Redstrom, & Wensveen, 2011; Zimmerman, Forlizzi, & Evenson, 2007). A design research process has similarities to the Product Innovation process. The design research process starts with the Grounding phase, in which the problem is studied from multiple perspectives. This phase is followed by Ideation, in which as many ideas as possible are generated. The next step is to create and explore the ideas in multiple cycles. This phase is called Iteration. The final phase is Reflection, wherein the outcome is critically assessed (Zimmerman et al., 2007).

The previous chapters have described the iterative design process of a monitoring system that supports the interaction between caregivers and clients with visual and severe/profound intellectual disabilities (V-S/PID). This chapter reviews this process and captures the lessons learned in a set of design guidelines (section 6.2). Secondly, a shift from the design for research approach to a design for innovation approach for the monitoring system is considered in section 6.3. This section describes the steps taken towards implementation in the current project and presents the lessons learned in a set of implementation guidelines.

6.2 Design guidelines

The iterative design process is an ongoing process. Although the cycle of understanding the context, findings, and theories is never-ending, it is also worthwhile to consider what it takes to deploy the Bioresponse system in real-life practice, bringing benefits to clients with visual and severe/profound intellectual disabilities and their caregivers. As mentioned in Chapter 5 (page 66), the Bioresponse system requires further development if the design for research process is continued. This iterative process has provided valuable insights into the context of the problem and therefore insights into the components that are required for such development of a monitoring system. Together with dr. H. IJzerman, a set of guidelines for the design of monitoring systems were developed. These guidelines explain what options regarding the hardware and software are available (at the time of developing the guidelines) and provide recommendations on which components to use, based on the experiences from the Bioresponse system and the systems from dr. H. IJzerman and his team.

6.2.1 Guidelines for the development of monitoring systems

Hardware

When developing monitoring systems, the first choice to make is the kind of external device to use. An external device is required for (temporary) storage and visualization. In a lab environment, a PC is the standard choice. Outside the lab, smartphones and tablets can offer a reasonable alternative for a PC, as they become more and more integrated into our daily lifestyle, and are rapidly developing in internal memory and visualization capabilities. At the time of developing the systems described in this thesis, wearables (like smartwatches) were not yet offering the capabilities of storage and visualization required for the studies addressed in part two of this thesis. Due to their rapid development, they are likely the future for monitoring systems.

The second step in the development of monitoring systems is deciding on accurate and non-intrusive sensor technologies. Traditional lab equipment often consists of units that can connect, stream, and/or log data from several sensors simultaneously while maintaining high accuracy. The disadvantages of these units are the use of gel electrodes that require regular replacement and often obtrusive placement on the body, and the required wired connections from the unit to external devices and to gel electrodes. This hampers the user's freedom of movement and comfort.

An alternative for lab equipment is activity trackers. They can be worn for longer periods of time, are low cost, and often provide immediate feedback. As these trackers are not developed for scientific research, they usually have low accuracy, and typically do not allow access to raw data. Another possibility is sensors backed by crowdfunding (e.g., the "AngelSensor"). Although crowdfunding often offers promising developments and innovative ideas, they usually underperform against expectations and are simply too unreliable for scientific projects (Tarus, 2016; Alois, 2014).

Small, wireless and highly accurate sensors in combination with smart textiles have been the solution for the systems described in chapters 4 and 5. Smart textiles can conduct electricity and have therefore the possibility to replace standard gel electrodes. They can easily be integrated into clothing and wearables and due to feeling like normal products, the sensor's intrusiveness can be lowered considerably.

Software

The next decision to make is software: choosing the operating system and communication method of one's external device. Currently, three available operating systems dominate the market – Android, iOS, and Windows. Presumably, Android is the best option, because it is open-source and most widely used in mobile devices (e.g., smartphones). Considering communication methods, Wi-Fi, Bluetooth, and Bluetooth Low Energy (BLE) are the most commonly used options. Bluetooth is preferred to Wi-Fi for communication. Wi-Fi requires a constant connection, which could lead to data loss on changing locations, while Bluetooth transmits information from the sensor to the mobile device directly. BLE can be favored over Bluetooth, as BLE is integrated into newer Android devices and is more efficient. A combination of BLE and Wi-Fi, where BLE transfers information from the sensor to the mobile device, and Wi-Fi transfers information from the mobile device to a server (albeit infrequent), might be preferred when collecting continuous data for weeks or even months.

Then sensor-specific software needs to be developed. Open-source methods are advocated here. The benefit of open-source code is that other developers can easily check, correct, build onto, and/or adjust code to the requirements of their study. GitHub is a common platform to share code because of the structure they offer. Other developers can fork the original code, and then post versions of their code as an attachment to the original code, thereby creating a database of code for related research. Unfortunately, using open-source software limits the types of sensors that could be used.

One note of concern in developing sensor-specific software is privacy. In this regard, data storage outside of the European Union through for example the Apple Research Kit is less than ideal. One solution to protect participants' privacy, suggested by IJzerman and colleagues, is by using https on the server, use e-mails and passwords to connect from apps to the server, and generating a private token for the app to send the information. This solution offers some basic security that decreases the chances of devices being hacked. Considerable attention needs to be devoted to moving this type of research forward (cf. IJzerman, Heine, Nagel, & Pronk, 2017).

6.3 Implementation guidelines

In this section, "implementation" is understood as the steps necessary for bringing a system to the real world; referring to the product innovation process of Section 6.1. This transition requires extra attention for the steps Considering (and re-considering) strategy and Product launch and use. Although the monitoring system described in this thesis has been developed as a part of a research process, it is a worthwhile goal to have the system available to care organizations and care professionals. The "Wereldcafé Bartiméus" meeting on February 5th, 2018 in Zeist, the Netherlands, inspired to start the process of marketing the Bioresponse system. The "Wereldcafé

Bartiméus" connected researchers of five projects from Bartiméus, including the Bioresponse project, with local companies (e.g., a lawyers office) to exchange ideas on marketing these Bartiméus projects. Inspired by this meeting, Prof. P. Sterkenburg concluded a presentation about her research projects within Bartiméus, which included the Bioresponse system, with a call for help with marketing these projects. A. Manni, treasurer of the Bartiméus family association, responded to this call and introduced B. Iedema to the researchers. As lecturer at the Erasmus Governance Institute and certified Emotional & Social Intelligence Coach, B. Iedema was looking for technology that can support trainees in noticing the strength of the emotions they experience during an exercise simulating difficult work situations (e.g., a bad news conversation). He saw an opportunity to market the Bioresponse system to corporate businesses as well as to care organizations, thereby increasing the number of potential users and reducing the development costs. B. Iedema and A. Manni established the company EmoClarity (www.emoclarity.nl) to market their version of the Bioresponse system and initiated a collaboration between EmoClarity, Bartiméus, Eindhoven University of Technology, and Vrije Universiteit Amsterdam. Based on this process of marketing the Bioresponse system, a set of guidelines is created for the implementation of monitoring systems.

6.3.1 Guidelines for the implementation of monitoring systems

Multidisciplinary teams

The first step in implementing a monitoring system is identifying key partners. Collaboration with care organizations is required as they have the knowledge concerning the user (e.g., what are the user's needs and the requirements a system needs to fulfill). Researchers hold the expertise to define the problem and to validate the solutions. Engineers and developers need to be included in the team to plan, create, and produce the software and/or hardware of the system. The involvement of business partners is crucial as they hold the knowledge to start-up a business, to build a network that includes manufacturers, distributors, and financiers. Marketing and communication experts need to be included to launch and promote the product.

To visualize the key partners for the Bioresponse system, a Value Flow model (p.154, Den Ouden, 2011) was created — from the perspective of the author. This model was selected since this method is specifically developed to describe value flows in complex systems with multiple members. This model has previously been successfully applied to the Smart Jacket, a system similar in complexity and stakeholders as the Bioresponse system (p.49, Bouwstra, 2013). The customers in the value flow model of the Bioresponse system are professional caregivers, parents, family, friends, and — most importantly — the client (Figure 6.1). Their experienced value of the Bioresponse system will be an improved quality of interaction. The service providers with whom the customers have direct contact are the health professionals (e.g., doctor or dentist), therapists (e.g., behavioral therapists or physiotherapists), and developmental psychologists. These service providers might be supported by the Bioresponse system by gaining a better understanding of the client's behavior, which in turn may lead to better health care, therapy, and support for the client. The Bioresponse system could travel with the client from the client's home to the service providers. However, for specific medical or therapeutic questions, it might be more productive to have a Bioresponse system available to the service providers. In this

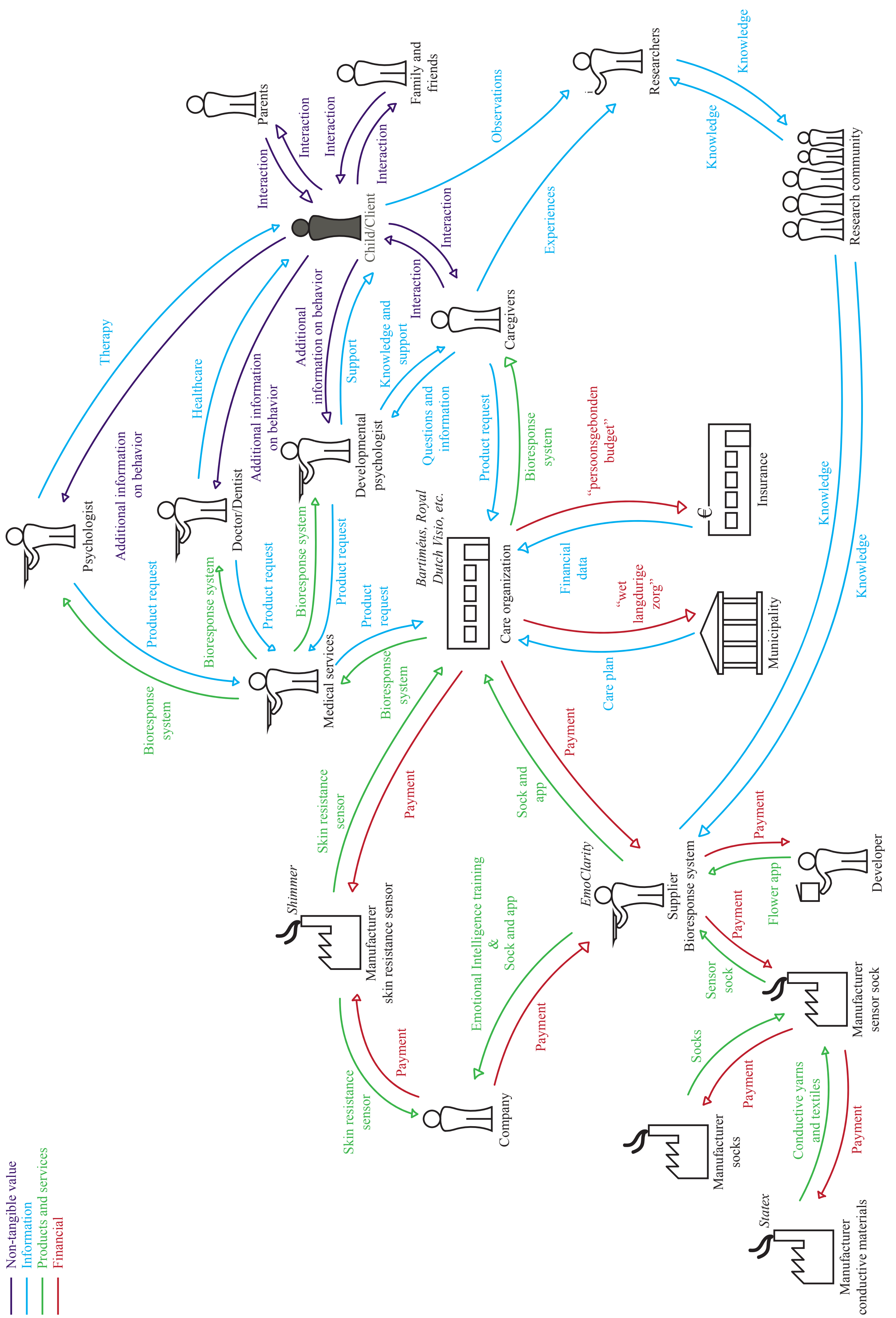


Figure 6.1 Value Flow model of the Bioresponse system.

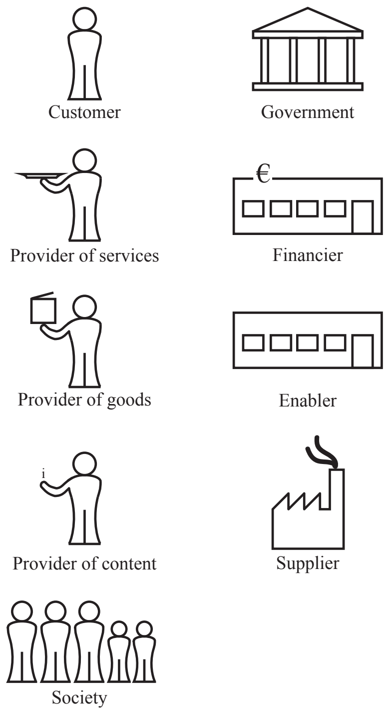


Figure 6.2 Explanation of the icons used in the Value Flow model

case, the system might be shared between service providers and managed through a medical services department.

The professional caregivers and medical services can request the acquisition of the Bioresponse system from the care organization, who will coordinate the acquisition with the supplier. In the Netherlands, the care that clients receive from a care organization is covered through insurance ("het persoonsgebonden budget") and the municipalities (in the law: "wet langdurige zorg"). The acquisition of the Bioresponse system for a client would be part of this funding.

In the current design, the Bioresponse system consists of three separate parts: a skin resistance sensor (the Shimmer 2R Biophysical module), a sensor sock, and a Flower app. The care organization can directly purchase the skin resistance sensor from the manufacturer (Shimmer, Dublin, Ireland). The sensor sock and the Flower app can be bought from the supplier (EmoClarity, Naarden, the Netherlands). EmoClarity will provide emotional intelligence training with the Bioresponse system and offer the Bioresponse system to corporate companies as well. EmoClarity will acquire the Flower app from a developer and the sensor sock from a manufacturer, who in turn has to obtain the materials for the sensor sock from other suppliers.

Collaboration agreement

When all key partners are identified, drawing up and signing a collaboration agreement is the next step. This is a time-consuming process as multiple persons from each party (e.g., a lawyer or a managing director) will read and make adjustments to the agreement; even though only one representative of each institution, university, or company will sign the agreement. In the agreement, all partners, a description of the monitoring system, the possession of patents or lack thereof, and previously received funding that made the development of the monitoring system possible are mentioned. Make sure to verify whether funding agencies or universities have set any limitations for cooperations with third parties before signing. Other elements to include in the cooperation agreement are the objectives of the collaboration and the role of each partner to achieve these objectives. Furthermore, it is advisable to define what knowledge and information are confidential, and what can be used in current and future projects and in lectures and classes. If the monitoring system contains an app, consider defining a license for the app in the agreement. Options for a license include exclusive/non-exclusive and/or transferable/non-transferable license. To find the best options to use for the license, consult with an IP advisor (often available within the university).

Separate products

Research design processes and innovation design processes have different aims. Where research processes generate knowledge through design, innovation processes create commercial designs. The products that result from each process will be markedly different, due to serving different goals. A monitoring system for research needs to collect raw physiological data that can be related to observations, (self-)reports, and environmental factors to be able to interpret the data. This comparison may result in new knowledge. A commercial monitoring system needs to provide feedback to the user in real-time for the user to be able to reflect on and potentially change his/her behavior. The features of each product will differ. For example, the research product will require data storage, while data storage in the commercial product will be highly undesirable as it is a privacy concern. Separating the two products by name, form, and functionality will improve communication and prevent confusion for users. It allows the monitoring system to develop without conflicting design requirements and complicated solutions.

6.4 Discussion

6.4.1 Research or innovation?

At the start of the design process, a decision is made on the approach to follow: design for research or design for innovation. In the case of the Bioresponse system, the approach was design for research. The iterative development process for the monitoring system has generated knowledge of the design requirements for a monitoring system and the components that compose a monitoring system. However, one approach does not have to exclude the other. A research approach can be transferred to an innovation approach. To achieve this transfer, specific knowledge on financing, manufacturing, marketing, distributing, and selling is required. New partners with commercial knowledge and experience are needed to make the design available to the target group and often a redesign of the monitoring system will be required. The features required for research can be removed and the design can be optimized for quick and easy manufacturing and assembly. It is also possible for different partners to independently work on one approach and share the knowledge so that both approaches can benefit. This is the case for the Bioresponse system. EmoClarity is developing — independent from the researchers involved with the Bioresponse system — their version of the Bioresponse system that will be commercially available. Meanwhile, a redesign of the Bioresponse system (as described in chapter 5) for research purposes is performed and related projects are established. For example, the Ph.D. project from H. Korving (Eindhoven University of Technology, Eindhoven, the Netherlands) that studies the sensor sock's ability to measure pain when connected to another tailor-made app (EMB & ICT, 2020).

6.4.2 Independence

Although the two different design approaches do not have to exclude one another, it is important that they remain separate processes. In the Netherlands Code of Conduct for Research Integrity, guidelines for good research practice are defined. Independence is named one of the five principles needed for good research practice. It is described as following: "*Independence means, among other things, not allowing the choice of method, the assessment of data, the weight attributed to alternative statements or the assessment of others' research or research proposals to be guided by non-scientific or non-scholarly considerations (e.g., those of a commercial or political nature)*" (Netherlands Code of Conduct for Research Integrity, 2018). Keeping the innovation and research processes separate ensures that they are independent of each other. This independence can be stated in the collaboration agreement together with who is responsible for which process.

6.5 Conclusion

The Bioresponse system has been developed in an iterative design process with a design for research approach. Reflecting on this process has revealed several key components that compose a monitoring system. The hardware consists of an external device (e.g., a PC or tablet) for data storage and visualization, and a sensor that needs to be portable, wireless, and unobtrusive — possibly combined with smart textiles to enhance comfort. For the software, the best operating system (e.g., Android or iOS) and communication method (e.g., Wi-Fi or BLE) have to be selected before sensor-specific software can be developed. In a later stage of the development, a transfer from a research approach to an innovation approach can be considered. For this transfer, partners with commercial knowledge and expertise are required. Important in this process is to identify all key partners (care organizations, researchers, developers, manufacturers, distributors, etc.) and to establish their role in the development process. A collaboration agreement between partners will define objectives, roles, confidentiality, licenses, and exchange of knowledge. Finally, separating the products of the research and the innovation process in name, form, and functioning will ensure better communication and more user-friendliness. In this regard, the future of the Bioresponse system will be twofold. First, research and development will continue to improve the Bioresponse system and gain new knowledge (e.g., can the system monitor pain). Secondly, a commercial system will be developed by EmoClarity so that care organizations will be able to buy the system for their clients.

PART II

VALIDATING THE BIORESPONSE SYSTEM

Preface

The first part of this thesis discussed the iterative development process of a monitoring system that supports (professional) caregivers in their interaction with persons with visual and severe/ profound intellectual disabilities (V-S/PID). This process has contributed to research with knowledge of how to design a monitoring system. The second part of this thesis will address the evaluation and validation of the Bioresponse system (the last iteration in the development of the monitoring system). This part starts with a vision for the role of monitoring systems. Not only can a monitoring system support the practice, but it could also be a tool for research as well. In this chapter, the role of, among others, the Bioresponse system in the field of relationship research is considered.

This chapter is based on: Frederiks, K., Sterkenburg, S., Lavner, Y., Cohen, R., Ruinskiy, D., Verbeke, W. & IJzerman, H. (under review). Mobile Social Physiology as the Future of Relationship Research and Therapy: Presentation of the Bio-App for Bonding (BAB). https://psyarxiv.com/xr8ma/

Chapter 7 Monitoring systems applied to research

7.1 Introduction

The study of human behavior is arguably one of the hardest sciences (Srivastava, 2016) since many of its components are highly interrelated and dynamic. Yet research concerning human behavior, specifically interpersonal relationships, generally occurs in a relatively isolated context: the lab. As a result, these studies are often left non-generalized towards real-life and unexamined in practice. The consequence of studying humans in isolation is that interpersonal processes have been interpreted as static and mostly internal to people's mental worlds (Agnew, Van Lange, Rusbult, & Langston, 1998). However, the premise that human social behavior is grounded in the social environment implies that cognition is much more distributed and much less "inside the head". Although lab studies allow us to formalize causality in our theories, the question remains to what extent these models are accurate depictions of real-life behaviors and, if these models are not accurate, which steps should be taken to improve models of human cognition and behavior.

Progress can be attained by incorporating modern technological innovations in real-life studies, so that the number of measurements (i.e., internal reliability) and the number of contexts (i.e., generalizability) dramatically increase, all the while increasing external validity and retaining the possibility to draw causal inferences. Movements away from the lab and towards daily experience sampling have been advocated recently (Hofmann, Baumeister, Förster, & Vohs, 2012; Thai & Page-Gould, 2018). However, a starting point of the *mobile social physiology* approach is the premise that human social behavior and cognition heavily rely on the social environment as an extension of one's own "head" (Smith & Semin, 2004). In addition, it takes as a starting point that patterns in human behavior are observed first before mechanisms are predicted.

Mobile social physiology uses technologies like wearable sensors, actuators, and analytical methods to more accurately pinpoint social (and often non-conscious) processes in real-life and likely negates many of the previous theoretical principles.[1] Further, mobile social physiological data collection may uncover more complex models of social behavior than what has previously been found in the lab. This will largely be due to the ability to study patterns in vivo, shifting

1 Notably, the processes studied now and pointed to here are made possible by advances in modern technologies. Twenty or thirty years ago, researchers did not have the availability of more advanced statistical programs that provide the analyses with the click of a button, nor did they have the availability of modern sensors and actuators that measure and manipulate human peripheral skin temperature with incredible precision. Finally, and importantly, psychological science has also seen a "revolution 2.0" where online frameworks like the Open Science Framework allow for easy data and code sharing and/or easy distinguishing between exploratory and confirmatory findings (through for example pre-registration; see also Spellman, 2015). All these developments put us at an unfair advantage when judging researchers from the past.

the focus from the lab to hardly-examined dynamics of homeostatic regulation and complex cognitive patterns in real-life relationships. The basis is co-regulation: more complex relationships can be detected and integrated into this framework to regulate allostatic load, allowing us to understand how modern social relationships still help us to regain homeostasis (Friston & Kiebel, 2009).

The aim of this chapter is to present a vision for monitoring systems, like the Bioresponse system, by introducing a new approach: mobile social physiology. Mobile social physiology is an experimental research approach that intends to interchange with causal-comparative research approaches. This interchange may allow for a more in-depth understanding of relationship theories in real-life situations. The mobile social physiology approach is grounded in a theoretical model laid out by Beckes, IJzerman, and Tops (2015) on interpersonal relationships. This chapter will start by extending this model with a co-regulation perspective that we see as unifying for the diverging theoretical perspectives in relationship research. Although the Bioresponse system is specifically developed to support caregivers in their interaction with people with visual and severe/profound intellectual disabilities, this system could also — when combined with other systems — become a tool to study relationships in real-life. This chapter introduces an integrated application — the Bio-app for Bonding — as a starting point to examine this new mobile social physiology approach. This application integrates four modules of applications developed to study, understand, and intervene (in) relationships in real life. The integration, the different modules, and the analytical methods used to create these modules are described in this chapter. Further, it is explicated how these methods can be used to quickly advance mobile social physiological research and its application.

7.2 Theoretical framework

7.2.1 The theory of Beckes, IJzerman, & Tops (2015)

Psychologists often assume that people have an internal, mental representation of others that helps them predict how to act towards other people. The brief summary of how an internal model is ostensibly formed is that people experience a situation (e.g., a loving and emotionally responsive parent) for which they form associative links in memory (e.g., when I am sad, my parent will hug me). They then apply this internal model later in life to know how to act in a novel situation (e.g., hugging a sad partner) when the relevant information is "primed" (e.g., through the sad face of the partner). As the internal model is seemingly unaffected by aspects like perception, it has been extended to understand nearly all relationship behaviors, which in turn have mostly been understood as consisting of higher-order processes, like responsiveness in close relationships (Reis & Gable, 2015), the role of relationship commitment in its maintenance (Rusbult, Olsen, Davis, & Hannon, 2004), and accommodation and/or forgiveness in close relationships (Agnew et al., 1998). Relationship quality, forgiveness, commitment, responsiveness, and accommodation can all be categorized under cognitive interdependence. [2]

2 The application of such higher-order cognitive representations is probably rooted in a long tradition that points to cognition as being "in the head" and relying on amodal representations. Central to this idea is the metaphor of the mind working as a computer, in which people perceive external stimuli and translate them to a "computer-like" language (like "0" and "1"'s; for a criticism of this perspective, see e.g., Barsalou, 1999, 2008).

The assumption that such a "social priming" sequence can be initiated through an "internal working model" has for long been criticized on theoretical grounds (e.g., Beckes et al., 2015; Fiske, 2002). Instead of deriving a string of internal mental processes, Beckes and colleagues (2015) suggested that such action sequences in close relationships first and foremost rely on perception-action mechanisms, perhaps akin to approaches that have become known as "automaticity". Yet automaticity principles depart from the principle that perceivers lack awareness of the process, control, and intentionality, and are efficient in their behavior (Bargh, 1994). People are thought to automatically and unconsciously mimic each other's emotional expressions (Chartrand & Bargh, 1999). In the automaticity literature, mimicking has been considered to serve as "glue" so that the mimicked person is more likely to affiliate. Like the concepts focusing on cognitive interdependence, the automaticity literature depends on habits and internal representations to facilitate interpersonal relations.

Contradictory, other research has shown that "automatic behavior" is not so automatic, not necessarily mimicked, and instead more context sensitive (Andersen, Moskowitz, Blair, & Nosek, 2007). People in high (and not in low) quality relationships do not mimic their angry partner, but instead respond with an affiliative smile (Häfner & IJzerman, 2011; Likowski, Mühlberger, Seibt, Pauli, & Weyers, 2008). Similarly, in high-quality relationships people increase their peripheral temperature when they notice their partner's or child's stress reaction (IJzerman et al., 2015; Vuorenkoski, Wasz-Höckert, Koivisto, & Lind, 1969), even though stress reactions typically induce a decrease in peripheral temperature (Vinkers et al., 2013). People's behaviors are typically in service of relationship maintenance. Further, the importance of "habits" (like relationship quality) in such behaviors suggests that temporarily "primed" changes in commitment, attachment, and relationship quality appear nigh impossible.

The "traditional" perspective is thus that people behave automatically and unconsciously in interpersonal relationships, which rely on "priming" sequences of internal models; be it conscious or not. In contrast, the assumption underlying mobile social physiology is that homeostatic regulation is the core goal of relationships, relying on direct perception-action sequences initiated upon detecting the partner's emotions.[3] From this perspective, higher-order mental constructs of responsiveness are difficult to prime, and instead habitually formed through frequent and dynamic activations that are first and foremost reliant on maintaining homeostasis. People, having formed a habit focused on being supported by the partner (or by a caregiver), respond supportively towards the partner upon noticing the partner's face, which calls upon basic perceptual mechanisms. They may respond by displaying a spontaneous smile to the partner's angry face and/or they may increase one's skin temperature to the other's sad face. The question remains: What are the underlying psychological and/or physiological processes and how can it be that people habituate in becoming responsive to others? The ideas supporting this view are emergent, to date still understudied, and not yet unified. Little empirical data (and surely little fine-grained, real-life physiological data) is available.

3 This does not implicate that mental representations play no part in interpersonal relationships. Instead, mental representations modulate responses, dependent on longer-term individual experiences throughout one's (relationship) development. One example is the concept of the internal model of attachment. From birth on, infants form a "model" that captures the reliability of the caregiver. This model has been found to be a relatively stable individual difference factor that predicts how people act in relationships (for a review, see Beckes et al., 2015).

7.2.2 Unifying Diverging Theoretical Perspectives in Relationship Research: Co-Regulation

Co-regulation is likely one of the core concepts to unify diverging perspectives in relationship science. It can be defined as "*the process by which relationship partners form a dyadic emotional system involving an oscillating pattern of affective arousal and dampening that dynamically maintains an optimal emotional state*" (p. 202, Butler & Randall, 2012). By co-regulating, the dyad can balance the allostatic load in more efficient ways. The co-regulatory approach assumes a "*bi-directional statistical dependence between relationship partners over time"* (p. 203, Butler & Randall, 2012; for an example of bi-directional statistical dependence related to the buffering of stress, see Figure 1 of Butler & Randall, 2012, p. 204).

This bi-directional dependence relies on principles of providing allostatic balance. Allostatic balance is a broader concept than homeostasis since it includes a "*coordinated variation of psychological and biological systems that optimize performance and minimize costs*" (p. 204, Butler & Randall, 2012). Vital to allostatic balance is the regulation of stress, which in its turn depends on pressing environmental demands (like temperature changes). These demands, evolutionarily, have hinged on a need for (and thereafter provision of) safety and security, and, in extension, the ability to explore (Bowlby, 1969).

For endothermic animals, safety and security relies on being safe from predators. For example, ostriches need to balance keeping out a watchful eye for predators and picking up food from the ground. Distributing looking out for predators over the group, increases the rate of eating and the amount of food the ostrich can take in, and decreases the individual cost of vigilance processing (Krebs, Davies, & Parr, 1993). Adult humans have a similar vigilance processing distribution. The activation of brain areas related to stress is reduced to a minimum when the participant's hands are being held during a small electric shock (Coan, Schaefer, & Davidson, 2006). These effects are more pronounced when the hand holder is someone familiar (e.g., a significant other) and/or the relationship quality is higher. The central idea is that —like ostriches — threat (and thus stress) becomes distributed over the dyad through a process of co-regulation. Next to vigilance processing, safety and security relies on being safe from the cold. For humans, drops in peripheral temperature (absent other beings) occur to preserve heat in the core. Human infants, for example, need others to help regulate their temperatures (their bodies are too small to do this by themselves). In one study, when a mother left the room in the Strange Situation [4], infants' peripheral temperature decreased and the temperature only returned to baseline once the mother returned (Mizukami, Kobayashi, Ishii, & Iwata, 1990).

Distribution of temperature and of risks are formative for interpersonal relationships in their simplest form. They later become "sociometers" as they become habituated into more stable relationship orientations. Recent findings, for example, show people's desire to socially thermoregulate is robustly related to attachment avoidance (Vergara et al., 2019). Central to

4 The Strange Situation, developed by Ainsworth (Ainsworth & Wittig, 1969), is a method to observe mother-child attachment and to classify the children's attachment security. The procedure consists of eight episodes. In the first 3 episodes, mother and child are exposed to a strange environment (the lab) and later to a stranger (an unknown research assistant). In the fourth episode, the mother leaves the room, where the child and the research assistant remain. The mother returns in the fifth episode and the research assistant leaves the room. The mother leaves the room in the sixth episode. The research assistant returns in the seventh episode, and the mother returns in the eighth episode (Van Rosmalen, Van der Veer, Van der Horst, 2015).

bonding is thus the degree to which the infant's needs of stress regulation and temperature can be outsourced, or co-regulated. One of the hallmarks of attachment theory is that the early experience of safety, security, and the ability to explore becomes a stable individual pattern to predict the behavior of others later in life. Attachment is also thought to form the basis for interaction styles in adult romantic relationships (Fraley, Waller, & Brennan, 2000), in group participation (Smith, Murphy, & Coats, 1999), in therapy (Mallinckrodt, Gantt, & Coble, 1995), and even in the "interaction" with deities (Kirkpatrick, 1998).

To summarize the theoretical framework, there are a few core principles when it comes to studying relationships. One of the starting principles is that people co-regulate. Second, co-regulatory processes primarily revolve around the distribution of vigilance processing and thermoregulation. Third, stable individual difference patterns in bonding and attachment develop, and these relate to individual differences in vigilance processing and thermoregulation (Vergara et al., 2019). Fourth, cognitively more complex dynamics (like forgiveness, commitment, and conscious forms of emotion regulation) are likely "built" on top of lower-order co-regulation patterns (Mandler, 1992). Although having defined the basic principles, concepts like bi-directional statistical dependence and allostasis are still too vague for a coherent theoretical model. How can one reliably study these to formalize the concepts?

7.3 Bio-app for Bonding

Co-regulation likely depends on a complex interrelated set of cues and responses between partners. Take, for example, the infant-caregiver relationship: The infant needs to cue the caregiver that it is cold and needs to warm up, and — like in other animals — crying is one way to signal this need (Awam, Catana, & Mortola, 2011). Parents provide complementary responses to soothe the infant. The Bio-app for Bonding (BAB) aims to combine the recording of co-regulation patterns, and social cues and responses between partners. With the use of this application, patterns of interrelated cues can be studied in greater detail, which allows for inferring connections between the cues and responses from partners.

The BAB integrates four modules of different research lines that independently study the infant-caregiver relationship in real-life. Each module and its original research line are described in detail below. The first and second modules explore co-regulation patterns: vigilance processing and thermoregulation respectively. The third module enables the capturing of social cues — in this case, the infant's cry. To support the interpretation of the recorded cues and co-regulation patterns, a fourth module — a self-report measure — is included in the app. Combining the modules and research lines in the BAB may uncover more complex models of social behavior.

7.3.1 Module 1: Vigilance processing

The first module aims at measuring and visualizing the co-regulation patterns of vigilance processing. Distribution of vigilance processing between two persons can be assessed through physiological correlates of stress. Measuring the distribution of vigilance processing can go from relatively simple (physiological measures) to very complex (inferences of why a person experiences stress in the job context). People have a different range in their capability

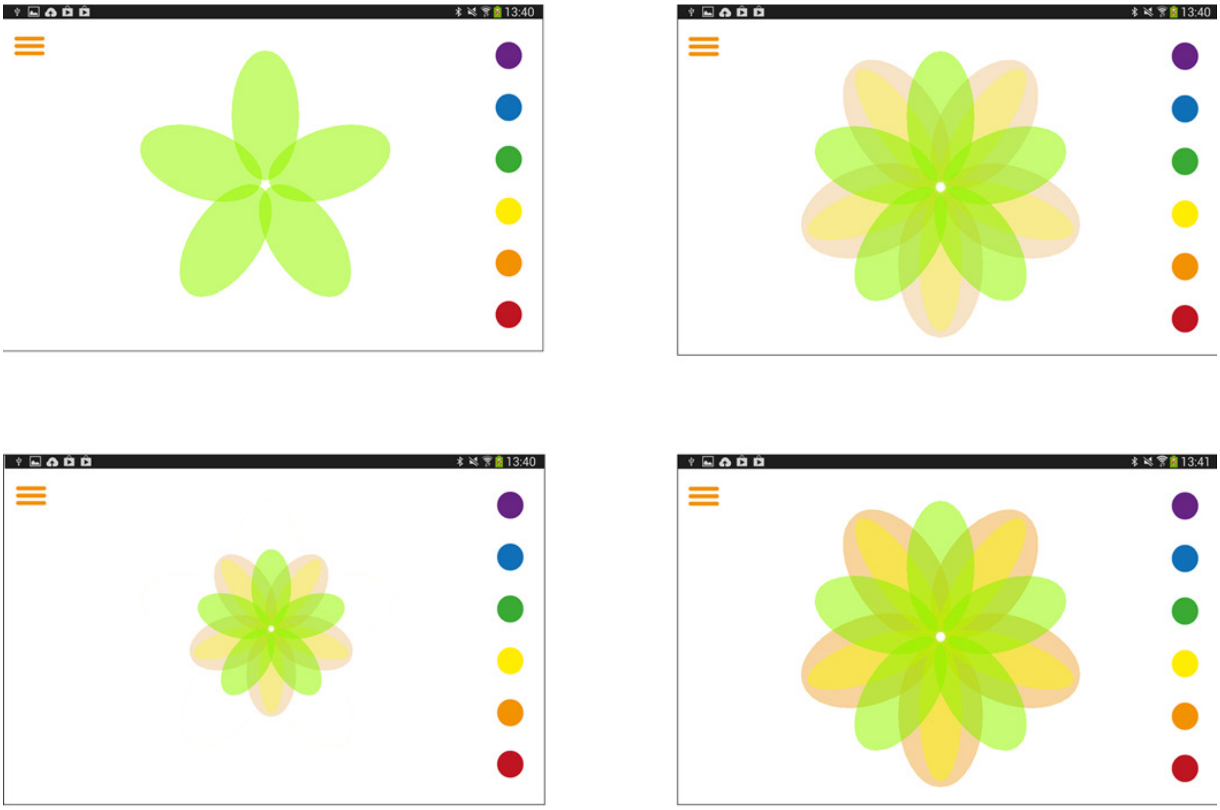


Figure 7.1 Flower app – Visualization of the skin resistance signal in the form of a flower.
Panel 7.1A: High arousal, low reaction to stimuli
Panel 7.1B: High arousal, medium reaction to stimuli
Panel 7.1C: Low arousal, high reaction to stimuli
Panel 7.1D: High arousal, high reaction to stimuli

of processing complexity and predictability in their close relationships. However, across the spectrum of intellectual development, the principle in terms of physiological correlates is the same, which is why physiological correlates are the preferred methods for the BAB. These physiological correlates have been studied at the level of the brain (Coan et al., 2006), stress hormones (Kirschbaum, Pirke, & Hellhammer, 1993), and through physiological signal monitoring (Giakoumis, Tzovaras, & Hassapis, 2013).

Measuring vigilance processing

Module 1 measures the need for vigilance processing with the use of the physiological signal skin resistance (SR). The SR signal is visually represented in the form of a flower. The module displays two elements of the SR signal: a tonic element and a phasic element.[5] The tonic element is visualized in a green flower that changes in size correspondingly to the alterations in the measured SR level. The tonic element is extracted from the raw SR data (as received from a Shimmer 2R Biophysical sensor) with a low-pass filter. The size (or, more accurately, the

5 The tonic element is a slow varying element, which indicates the overall level of sympathetic arousal (Benedek & Kaernbach, 2010a,b). The fast-varying phasic element shows a steep increase and a slow recovery of skin conductance (Benedek & Kaernbach, 2010a,b). The phasic element is also referred to as "skin resistance response" (SRR) (Benedek & Kaernbach, 2010b; Ogorevc, Geršak, Novak, & Drnovšek, 2013). SCR indicates stimulus-specific responses or non-specific responses (e.g., a person's thoughts) (Benedek & Kaernbach, 2010b).

Figure 7.2 The development of a mobile social physiology system – the Bioresponse system.
Panel 7.2A: Sticky electrodes attached to the child's foot for EDA measurements while using the Med-Storm Pain Monitor.
Panel 7.2B: Fabric electrodes (replacing the gel electrodes) integrated in the sole of a sock for comfortable EDA measurements.
Panel 7.2C: The Shimmer™ 2R BioPhysical sensor module connected to the snap fasteners of the sock.
Panel 7.2D: The Bioresponse system used in pilot study with an adult with a visual and severe intellectual disability and his caregiver.

radius) of the flower is determined by dividing the tonic value by a constant. The radius has a lower and an upper threshold (meaning alterations below or above a certain tonic value are not visible) to make sure the flower remains visible on screen.

The phasic element is visualized in the flower through additional (orange) petals. The phasic element is extracted using a high-pass filter on the tonic value. To calculate the number of skin resistance responses per second, each phasic value is compared with the previous phasic value; if the difference exceeds a set threshold, the change is registered as a peak and all peaks in a period of 1 second are summed. These peaks are visualized in the flower through additional (orange) petals appearing when peaks are detected. If the number of peaks exceeds a threshold, the opacity of the orange petals is gradually increased (thus making the petals visible). When the number of peaks drops below the threshold, the opacity is gradually decreased and the petals fade out (see Figure 7.1).

Module 1 is developed with the intention to measure SR with a Shimmer 2R Biophysical sensor combined with a smart sock (see Figure 7.2C). The smart sock has two integrated textile electrodes made of Shieldex® textile (see Figure 7.2B). These textile electrodes replace the gel electrodes (Figure 7.2A), commonly used for SR data collection, to offer more comfort to the wearer and enable continuous sampling. Each textile electrode is connected through Shieldex® conductive yarn to a snap fastener, which allows for connection with the Shimmer sensor (in a similar manner as connecting a gel electrode to the Shimmer sensor via a snap fastener). The Shimmer sensor streams data wirelessly via Bluetooth to an Android tablet or smartphone.

Research examples of vigilance processing measurement

The measurement of the need for vigilance processing is valuable in relationships with people whose signals that indicate the need to "outsource" vigilance processing are challenging to read, understand, and interpret. Newborn infants with Prader-Willi Syndrome (PWS) typically have severe hypotonia, which is expressed in a poor cry, reduced movement, and a weak suck reflex (McCandless, 2011; Reus et al., 2011). The infant's development of more complex social interaction skills that allow others to read, understand, and interpret signals that indicate the infant's needs to "outsource" vigilance processing is severely delayed. The author and colleagues sought to visualize Autonomic Nervous System (ANS) activation of children with PWS so that the parent can more directly and more accurately support his or her child (see Chapter 3). The visualization functions as an additional cue for parents to better read, understand, and interpret their infant's signals (for an example of the underlying data for this visualization, see Chapter 3, page 30).

In the studies described in chapters 9, 10, 11, and 12, module 1 is used to visualize the ANS activation of people with visual and severe or profound intellectual disabilities (V-S/PID) (Figure 1D). The visualization of the client's vigilance processing aimed to support professional caregivers in attuning better to their client. People with V-S/PID express their needs and wishes using subtle communication signals like gestures, vocalizations, and movements, which are difficult for caregivers to understand and interpret (Hostyn & Maes, 2009). It is expected that — through caregivers better attuning to their clients — clients have more opportunity to develop. This development may lead to the reduction of negative behaviors, like challenging behavior, and the increase of positive behaviors, such as joint attention. In this way, module 1 would through measuring co-regulation patterns support the development of higher-order constructs, such as interaction quality and affective mutuality. This has been seen before in a study by Schuengel, Sterkenburg, Jeczynski, Janssen, and Jongbloed (2009), wherein they measured vigilance processing in a real-life therapeutic setting with persons with a severe intellectual disability and discovered a buffering effect of a secure relationship on their stress levels.

7.3.2 Module 2: Thermoregulation

The second module is developed to measure co-regulation patterns of thermoregulation. Co-regulation of body temperature is dependent on sharing body heat, but temperature regulation has extended to already more complex social interactions: Social exclusion for example leads to a lowering of peripheral temperature (IJzerman et al., 2012), while a variety of "higher-order" relationship behaviors (like projecting relationships onto inanimate objects; IJzerman et al., 2015) have been linked to social thermoregulation (for an overview on co-thermoregulation, see IJzerman, Heine, Nagel, & Pronk, 2017). Some early research has shown, for example,

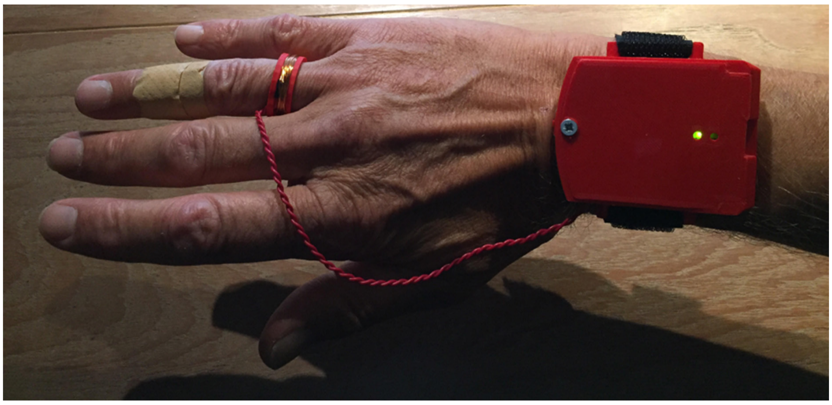


Figure 7.3 MyTemp Sensor. The sensor is attached to the finger via tape. The wristband functions to power the sensor.

that mothers' peripheral temperature rises when they hear their infant's cry (Vuorenkoski et al., 1969).

Measuring thermoregulation

For the measurement of the co-regulation patterns thermoregulation, H. IJzerman and his team developed the app called Closeness. The closeness app measures thermoregulation with the use of the physiological signal skin temperature (ST). The app dedicates one Android phone to one sensor (IJzerman, Ligtenberg, & Verbeke, 2017). It reads out its broadcast signal, registering the sensor's ID, the strength of the signal (representing the distance to the sensor), and skin and environmental temperatures. This collected data is synced over an Android SyncAdapter with a remote server. The app offers the possibility to easily update server information (for other users) and participant information on the app itself. Furthermore, two different mac addresses can be entered: one for the person being measured and one for the partner. The app then automatically recognizes when the partner is within 4 meters and adds a 1 to the database when the partner is close and a 0 when the partner is further than 4 meters.

The Closeness app is developed to collect ST data from a MyTemp sensor. The MyTemp sensor is a wrist-worn sensor that has a wired attachment to the index finger (Figure 7.3). The sensor is attached to the finger via tape. The wristband functions to charge the sensor. Its current sensor has a bias of < 0.1 degrees Celsius (although it can only measure every 5 seconds; Bongers, Hopman, & Eijsvogels, 2018). The current solution is not yet used for commercial purposes; however, it is adequate for research requirements. The sensor sends ST data via Bluetooth Low Energy (BLE) to an Android phone, and from the Android phone to a server (Van Emden, 2015).

7.3.3 Module 3: Social cues detection

Module 3 registers the infant's social cues. Measuring these cues is key for understanding co-regulation patterns, as these patterns are likely dependent on these social cues. Crying is a common way for the infant to signal its needs to the caregiver. A parent responds by providing care to the infant or by soothing the infant. Early research has shown that in an unconscious response mothers' peripheral temperature rises when they hear their infant's cry.

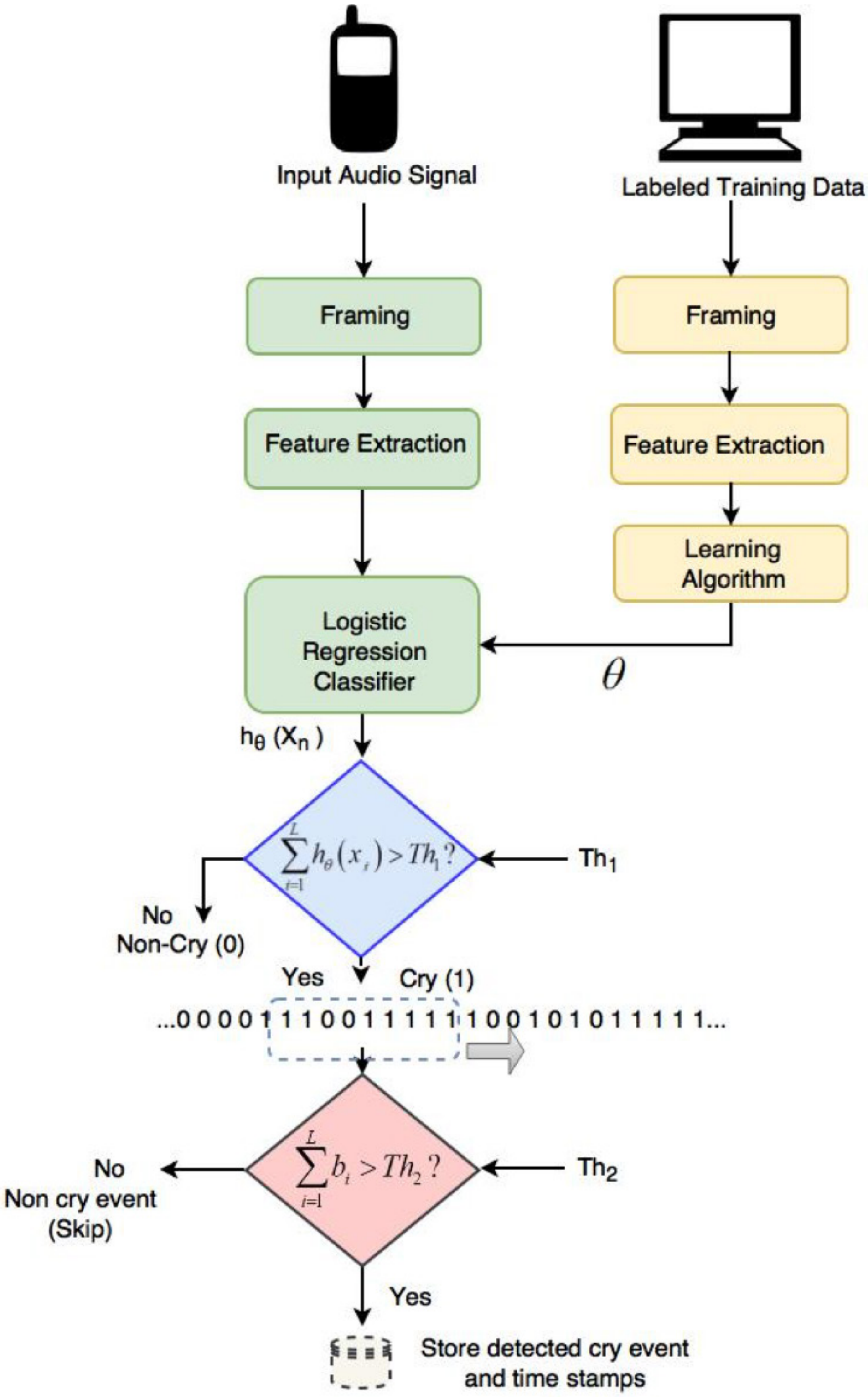


Figure 7.4 A data flow diagram of the supervised machine learning detection algorithm.

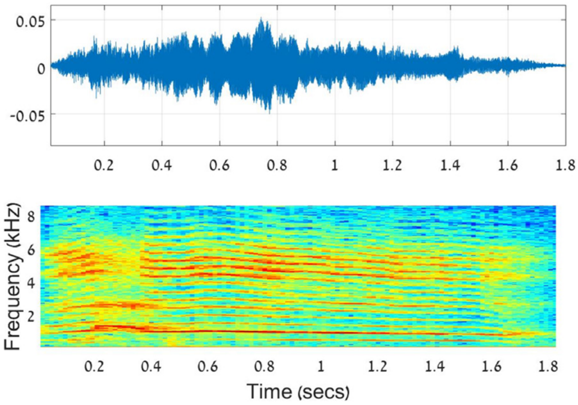


Figure 7.5 Developing the Crying algorithm.
Panel 7.5A (top): Representation of the infant cry: The time waveform of an audio signal that contains a single cry burst.
Panel 7.5B (bottom): Representation of the infant cry: The corresponding (narrow-band) spectrogram, characterized by a harmonic structure, where each horizontal line represents a partial harmonic. The frequency of this partial harmonic is nearly an integer multiple of the fundamental frequency.

Detecting social cues

The infant's social cues are recorded by an automatic baby cry detector that processes, in real-time, audio data obtained from the phone's microphone, and looks for onsets of a baby cry. Audio segments where a baby cry is spotted are stored together with the corresponding time markers (Figure 7.4).

The algorithm is based on a regularized logistic regression classifier [6] (Deng, Sun, Chang, & Han, 2014). It uses the characteristics of the cry signal [7] — a fundamental frequency (250-600 Hz, Várallyay, 1999, 2007) and a harmonic structure (see Figures 7.5A and 7.5B) as the parameters. This model was evaluated by establishing the detection rate versus false-positive rate. [8] For examining the co-regulatory patterns between a baby and a caregiver, a high detection rate is required. However, a low false-positive rate is perhaps more important, to avoid mixing the data with nonrelated events, which may hinder meaningful conclusions (and record noises that are privacy-sensitive). The logistic regression classifier yielded a detection rate of 86% and a false-positive rate of 2.5%. However, to obtain a much lower false-positive rate, a detection

6 A baby cry is a voiced signal, which means that its production involves periodic movements of the vocal folds, produced by a rapid flow of air through the larynx. This in turn generates a periodic excitation which is transferred through the vocal cords and creates the cry sound.

7 The logistic regression can be viewed as a hypothesis function $h_\theta(x)$, which approximates the probability that a given audio segment i contains a baby cry, corresponding to an input feature vector derived from that segment $x^{(i)}$. For the hypothesis function a sigmoid (logistic) function is used, where $h_\theta(x) = 1 / (1 + e^{-\theta^T x})$, and θ is a vector of weighting parameters. Given the training dataset with the feature vectors and their corresponding labels and a pre-defined error function, the parameters are set to minimize the error function using a gradient descent algorithm.

8 The detection rate (also known as sensitivity or recall) is defined as the ratio between the number of true-positive events (i.e., the number of cry events correctly identified [true positives]) and the total number of cry events in the recording set [true positives + false negatives]. The false-positive (or false-alarm) rate is defined as the ratio between the number of false positives (non-cry events identified erroneously as cry events) and the total number of non-cry events in the recording set (true negatives + false positives).

rate of 50% was set for the logistic regression classifier, which received a false-positive rate of 0.07%.

The algorithm is developed based on several tens of hours of audio recordings made by parents with babies in the Netherlands (Lavner, Cohen, Ruinskiy, & IJzerman, 2016). Two hours of recordings were annotated down to the millisecond, marking the various sounds, like crying or parents talking, resulting in more than 50 different event types and several tens of cry events. The algorithm was developed by first dividing the audio signal into segments of 100 milliseconds. Next, a set of audio features — including the Mel-Frequency Cepstrum coefficients (Quatieri, 2002), the fundamental frequency of the signal (pitch), harmonicity factor (Cohen & Lavner, 2012), harmonic-to-average power ratio (Cohen & Lavner, 2012), short-time energy, and zero-crossing rate — was computed from each segment. One feature vector, consisting of the features mentioned above, was computed for each segment. Next, the data was divided into two sets: A training set, containing the first several minutes of the audio recording, and a test set, comprised of the remaining data. In the training procedure, a probabilistic model for distinguishing the infant cry from other sounds is formed using regularized logistic regression.

7.3.4 Module 4: Interpretation

A classic – and justified – criticism of relying on physiological correlates (like peripheral temperature or skin resistance) alone is that they are underspecified to understand psychological states (Cannon, 1927; James, 1884). Increases in peripheral temperature could for example indicate excitement, affection, or anger (Ekman, Levenson, & Friesen, 1983). Understanding co-regulatory patterns (with peripheral temperature from a partner or crying of an infant) already aids in better extracting meaning of said physiological correlates. However, just measuring physiological co-regulatory patterns is still insufficient, therefore self-report remains crucial in understanding such physiological dynamics.

Measurements to support interpretation

In the mobile social physiology approach, attachment styles are central to understanding self-reported states in relation to co-regulation and can be more generally understood as a form of "predictive coding" of allostatic balance (Beckes et al., 2015). Predictive coding can be understood as a "*multi-level bidirectional cascade, of "top-down" probabilistic generative models with the core predictive coding strategy of efficient encoding and transmission*" (Clark, 2013, p. 183). Central to efficient encoding and transmission is survival and regulation of metabolic resources. These resources can – as a rule of thumb – be understood through an "economy of action" (i.e., more energy needs to come in than exerted; Proffitt, 2006). Bonding to other animals has thus generally evolved – at least in altricial animals – to support infant survival and to cope with the environment more efficiently.

Beyond considerable evidence in altricial animals, this view is supported by research in human subjects in the fields of co-regulation (Gottman & Levenson, 1992), social thermoregulation (IJzerman & Hogerzeil, 2017), and social support (Beckes & Coan, 2011). Even in humans, it is clear that avoidant individuals consume more glucose and have higher fasting glucose levels (Ein-Dor et al., 2015), and that people who are avoidant are less energized by loved ones (Vergara et al., 2019). There is also considerable evidence of the importance of monitoring one's own bodily needs for interpersonal bonding (Troisi, D'Argenio, Peracchio, & Petti, 2001). Predictive coding for these processes can be more accurately explained through something that has become known as the "Free Energy Principle" (FEP).

The Free Energy Principle (FEP) has its roots in "thermodynamic free energy". Its central underlying idea is that "*all (viable) biological organisms resist a tendency to disorder as shown by their homeostatic properties and must therefore minimize the occurrence of events which are atypical ('surprising') in their habitable environment*" (Buckley, Kim, McGregor, & Seth, 2017, p. 2). By minimizing the amount of stress and temperatures deviating from homeostatic levels, the organism minimizes the unknowable (thereby minimizing the amount of resources needed for such deviations known as "free energy").

As a core principle, partner responsiveness, commitment, and other self-reported states or traits in close relationships fall under FEPs; insofar as these self-reported states relate to minimizing the occurrence of atypical fluctuations of the environment, specifically pertaining to those which used to be life-threatening and which are central to attachment processes (stress and cold temperatures). The way to incorporate self-reported states is to ask participants at regular intervals about their moods, their perception of their own and their partner's responsiveness and commitment (Hofmann et al., 2012; Thai & Page-Gould, 2018). A form of experience sampling is integrated into the Bio-app for Bonding. These aspects of co-regulation are anticipated to become even more important for more complex social interactions, such as interactions in social groups (like work teams).

Thus, as a general starting principle, experience sampling studies in the field of interpersonal relationships should start taking into account 1) co-regulatory strategies and 2) predictive coding accounts and free energy principles more generally (Friston, 2010). It is possible that these principles do not hold, but by providing the methods and principles, falsifiable departure points are provided.

7.4 Reflection

The methods, described in the previous section, only allow for indirect causal inferences, since these methods do not allow the experimental manipulations that are required in psychology for inferences that a change in one variable leads to a change in another. However, once co-regulatory dynamics have been charted, it will become possible to engage in hypothesis-driven research through testing of experimental manipulations. Even the equipment is becoming available for this.

For example, the "EMBR Wave" is an actuator technology, that can manipulate peripheral temperature at the wrist in participants' daily life and could be pre-programmed based on descriptives from deep learning approaches, depending on what is necessary to create a functional co-regulatory pattern in a relationship (EMBR Labs, 2017). The lab of H. IJzerman has developed scripts in PsychoPy to manipulate peripheral temperature via the EMBR wave via the computer, and connecting the EMBR Wave to the BAB is a goal for the near future. Similarly, the "Doppel" is a wearable device that has been successfully shown to manipulate heartbeat-like tactile stimulation to alter stress levels before public speaking (Azevedo et al., 2017). Thus, not only observing through sensor technology is now possible (through the discussed app and the data-driven methods), manipulating in real-time (and responsive to the partner) through actuator technology is realistic in the near future. The applications for (relationship) therapy are easy to imagine and within reach.

7.5 Conclusion

This chapter has presented a vision for monitoring systems wherein these systems can not only be a supportive tool for the practice, but also for research itself. They may offer the ability to study co-regulation patterns in real-life situations, which in turn may create new insights into higher-level relationship constructs. The Bioresponse system, specifically, may support a better understanding of co-regulation patterns (for example, stress), of the client's behaviors, such as challenging behavior or joint attention behavior, and of the client-caregiver relationship, like the interaction quality and the affective mutuality of the dyad.

8

Preface

The development of the monitoring system that supports (professional) caregivers in their interaction with persons with visual and severe/profound intellectual disabilities (V-S/PID) has proven that physiological signal monitoring is suitable as a measure of (emotional) arousal for children with Prader–Willi syndrome (addressing research subquestion 1b "Can technologies, developed to measure (emotional) arousal for persons without disabilities, also measure (emotional) arousal for persons with V-S/PID?"). As the subtle communicative behavior of persons with V-S/PID is challenging to notice, interpret, and understand, it is critical that a monitoring system not only can measure (emotional) arousal but can do so accurately. In this chapter, the third iteration of the monitoring system — the Bioresponse system — is evaluated with non-disabled subjects to determine the accuracy of the monitoring system as a measure of (emotional) arousal (to answer research subquestion 2a "How accurately can a monitoring system measure (emotional) arousal?").

Chapter 8 Validating the accuracy of the Bioresponse system with non-disabled subjects

8.1 Introduction

Stress has been a topic of considerable interest for researchers. Mid-twentieth century, Selye was the first to use the term stress, which he described as a bodily response to changing demands from the environment (Sharma & Gedeon, 2012). This definition was later revised to stress consisting of a stressor – an emotional or physical stimulus that threatens homeostasis or is perceived as threatening – and a stress response – a bodily reaction to restore homeostasis (Chrousos, 2009). Homeostasis is the body's inclination to maintain physiological variables through physiological processes at a predefined set-point (Woods & Wilson, 2013). Koolhaas and colleagues (2011) have questioned this definition of stress, since anticipation of behavior and metabolic demands do influence physiological variables as well, but are not a threat to homeostasis. They proposed a new definition wherein "stress should be restricted to conditions where an environmental demand exceeds the natural regulatory capacity of an organism, in particular situations that include unpredictability and uncontrollability" (Koolhaas et al., 2011, p. 1291). In this thesis, the definition of Koolhaas and colleagues (2011) is adopted.

8

Stress can be beneficial since it can increase alertness, focus, and productivity. However, chronic stress has serious implications, ranging from reduced productivity and impaired decision-making to anxiety, fear, and serious health problems that include among others heart diseases, increased blood pressure, and diabetes (Choi, Ahmed, & Gutierrez-Osuna, 2011; Giakoumis, Tzovaras, & Hassapis, 2013). This has stimulated researchers to find ways to measure stress. The first method to measure stress is through self-report. Stress self-report questionnaires can be divided into two categories: (1) questionnaires scoring the occurrence or frequency of stressful events in a given period of time, and (2) questionnaires enquiring about the subjective experience of the participant. A commonly used subjective self-report questionnaire — a category 2 questionnaire — is the Perceived Stress Scale (PSS) (Cohen, Kamarck, Mermelstein, 1983). The PSS measures the participant's subjective experience of the severity of life's stressful events and their ability to cope with these events on a Likert scale (Taylor, 2015). Another subjective measure is the Stress Appraisal Measure (Peacock & Wong, 1990). The Stress Appraisal Measure evaluates anticipatory stress on six subscales (Controllable-by-self, Threat, Centrality, Uncontrollable, Controllable-by-others, Challenge), which are scored on a 5-point Likert scale ranging from 'not at all' to 'a great amount' (Peacock & Wong, 1990). One self-report method to measure the frequency of stress — thus a questionnaire belonging to the first category —is the Depression, Anxiety, and Stress Scale (DASS), in which three subscales (depression, anxiety, and stress) are scored on a 4-point Likert scale ranging from 'did not apply to me at all' to 'applied to me very much or most of the time' (Lovibond & Lovibond, 1995; Soysa & Wilcomb, 2015). Another common subjective self-report questionnaire is the Spielberger State-Trait Anxiety Inventory (STAI). The STAI exists of two parts: 20 items on how the participant currently feels (State Anxiety) and 20 items on the general feelings of the participant (Trait Anxiety) (Marteau & Bekker, 1992). A more intuitive questionnaire of subjective stress is the Self-Assessment Manikin (SAM). The SAM is a standardized form wherein the rating scales use visuals rather than words or numbers to rate participant's responses (Bradley & Lang, 1994). The SAM consists of three scales: Arousal, valence, and dominance and each scale is rated on a seven-point Likert scale of visuals.

Another method to measure stress is to measure its influence on the body. Two bodily systems can indicate stress: the hypothalamic-pituitary-adrenocortical axis and the sympathetic-adrenal-medullary system. The hypothalamic-pituitary-adrenocortical axis regulates hormonal responses, like the secretion of cortisol hormone, as a reaction to stress responses. Cortisol can be measured in saliva, blood, or urine (Ertin et al., 2011; Okada et al., 2013). The sympathetic-adrenal-medullary system mediates responses from the autonomic nervous system (ANS) (Ertin et al., 2011). The ANS transports impulses from the central nervous system to the organs, enabling the body to adapt to changes. Stress responses and emotional arousal influence the physiological balance of the ANS (Mokhayeri, Akbarzadeh-T, Toosizadeh, 2011; Sharma & Gedeon, 2012). This influence can be measured through monitoring skin conductance (SC), electrocardiogram (ECG), heart rate variability (HRV), blood volume pulse (BVP), blood volume pressure, electromyogram (EMG), and electroencephalogram (EEG) (Giakoumis et al., 2013; Sharma & Gedeon, 2012).

The Bioresponse system, designed by M. Croes, L. Vork, and P. Peters (Eindhoven University of Technology), measures stress and emotional arousal with the use of skin resistance measures in the home environment of persons with severe/profound intellectual disabilities (S/PID). The measured stress and emotional arousal levels must be accurate. When the system falsely indicates stress/emotional arousal, caregivers might respond incorrectly to the client's signals and thereby actually causing stress for the client. In the case where the system fails to indicate stress/emotional arousal, the Bioresponse system would fail to provide added value to its users. This chapter aims to verify that the stress/arousal measured by the Bioresponse system corresponds to one's experience of stress/arousal. Since persons with S/PID cannot use written or spoken language to verify the system's measurements, an experiment involving non-disabled subjects is used to verify the physiological measure of the Bioresponse system with a self-reported measure.

8.2. Methods and materials

8.2.1 Participants

This experiment was conducted with 22 Ph.D. students of the Eindhoven University of Technology, Eindhoven, The Netherlands. The mean age of the participants was 28.86 (SD = 2.95) and eight participants were male. All participants provided written consent for participation prior to the experiment. Inclusion criteria were: participants are older than 18 years and are not color blind (due to the nature of the experiment's tasks).

8.2.2 Procedure

The duration of the experiment was approximately 30 minutes. The experiment started with a general explanation about the setup of the experiment and the opportunity for the participants to ask questions before signing the consent form. After signing the consent form, the participant was requested to put on the Bioresponse sock and attach the Shimmer™ sensor to the sock. Participants performed three stressor tasks: (A) a 1-second-interval Stroop color-word test, (B) a 2-second-interval Stroop color-word test, and (C) an arithmetic test. Participants were randomly divided into three groups. Each group had a different task order: Group 1 had the order ABC, group 2 followed the order BCA, and group 3's order was CBA. All stressor tasks are preceded by a two-minute deep-breathing exercise (https://www.youtube.com/watch?v=Tol3CFscKBc&t). After each task (deep breathing, Stroop color-word, or arithmetic task) the participant was asked to fill in the self-report questionnaire.

The Stroop color-word test elicits mental stress by requiring that participants focus on one feature and block out other features (Mokhayeri et al., 2011). During the test, the participant is requested to name the font color of the word on the computer screen by speaking out loud. The test consists of two kinds of stimuli: congruent stimuli and incongruent stimuli. The congruent stimuli are words with matching ink colors and meanings (e.g., red). The incongruent stimuli have a mismatch between the meaning and the ink color of the words (e.g., purple) (Mokhayeri et al., 2011). The congruent and the incongruent stimuli are shown to the participant in randomized order.

8

In the arithmetic task, participants are requested to say out loud the answer to the arithmetic problem shown on their computer screen (for example: 922 + 407 = ?). Participants have four seconds to answer the question before the computer automatically displays the next question. The arithmetic task elicits mental stress due to the limited time for each question.

8.2.3 Instruments

Self-Assessment Manikin

Since this experiment aims to validate the participant's stress levels as measured by the sensor sock with the stress the participant actually experienced, a subjective self-report questionnaire is required. The self-report measure used in this study is the Self-Assessment Manikin (SAM). The advantage of the SAM over other subjective questionnaires is that it takes little time to fill out; therefore, it can be used multiple times in a short period of time. The SAM consists of three scales: Arousal, valence, and dominance. Each scale is rated on a seven-point Likert scale with the valence scale ranging from an unhappy face to a happy face, the arousal scale ranging from a sleepy figure to an excited figure, and the dominance scale ranging from a small figure to a large figure (Figure 8.1). Morris (1995) compared the SAM to Mehrabian and Russell's semantic differential procedure and achieved correlation coefficients of .94 for arousal, .94 for valence, and .66 for the dominance scale.

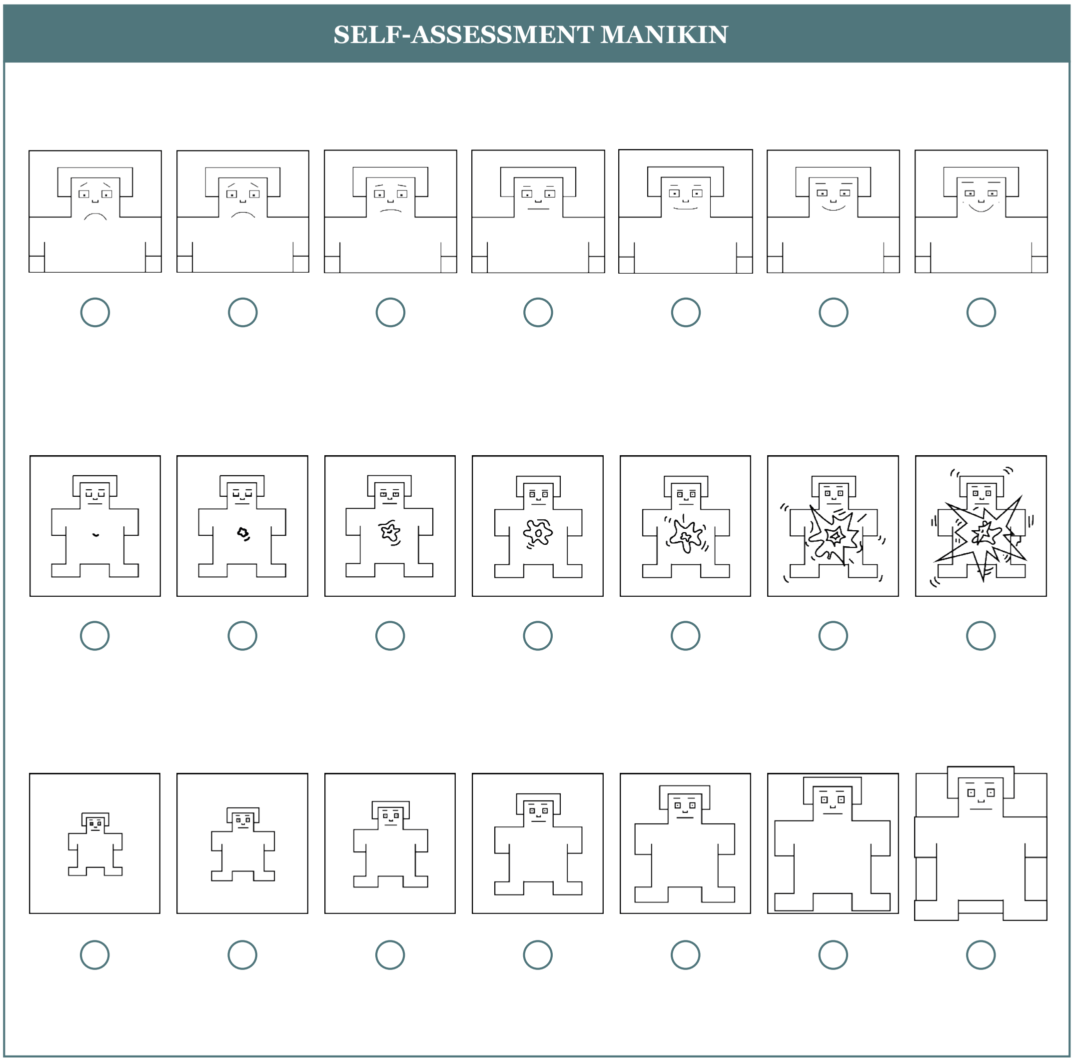


Figure 8.1 The self-assessment manikin questionnaire as used in the experiment.
Panel 8.1A (top scale): Valence scale
Panel 8.1B (middle scale): Arousal scale
Panel 8.1C (bottom scale): Dominance scale

The Bioresponse system

Physiological signals, and specifically electrodermal activity, can be used as an objective measure of stress (Yu, Funk, Hu, Wang, & Feijs, 2018; Giakoumis et al., 2012). In this experiment, the Bioresponse system was used as an objective measure of the participants' stress levels. The Flower app did record the skin resistance data, however without showing the flower as feedback. A blank screen was displayed to prevent influence from the feedback on the electrodermal measurements.

8.2.4 Analyses

The skin resistance data is extracted for each of the six tasks separately (3 deep breathing exercises, 2 Stroop color-word tests, and an arithmetic task). The deep breathing exercises received the label 'relaxation task', while the Stroop color-word tasks and the arithmetic task were labeled

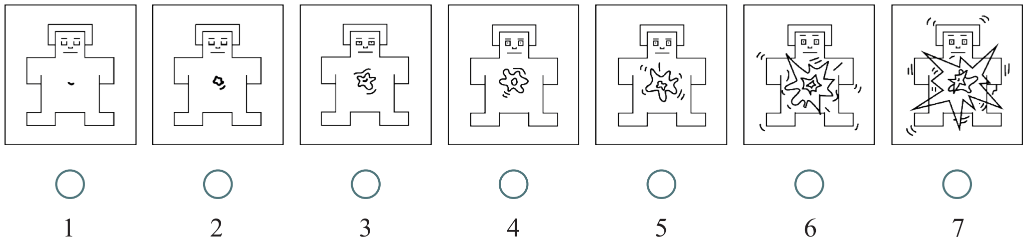


Figure 8.2 The labels applied to the arousal scale of the SAM for the SVM classification.

as ‘stressor task’. Skin conductance (SC) data was calculated from the skin resistance (SR) data, using the formula SC=1/SR. For each task, the mean skin conductance value was calculated. Each relaxation task was then paired with the stressor task that immediately followed that relaxation task; thereby creating three pairs of relaxation–stressor pairs per participant and 66 relaxation–stressor pairs in total.

Two paired t-tests ($\alpha = 0.05$) compared the relaxation tasks to the stressor tasks; one paired t-test used the mean skin conductance data, and the second paired t-test was performed on the SAM scores. The sensor sock is considered accurate when the result of the t-test comparing the mean skin conductance data is significantly different between relaxation tasks and stressor tasks, and as inaccurate when this result is not significant. The t-test comparing the SAM scores serves to check that the relaxation and stressor tasks are indeed perceived as different by the participants.

The accuracy of the sensor sock is further analyzed using a machine learning method: A support vector machine (SVM) algorithm. SVM algorithms are suitable for classification problems (Hsu, Chang, & Lin, 2003). In an SVM algorithm, the data is split into two groups: (1) the training set that includes the labels, and (2) a test set that does not contain the labels. The algorithm uses the training set to create a model wherein the data is divided into groups based on their assigned label and the data’s features. This model is then used on the test set data, which receives a label from the model based on the data’s features (Hsu et al., 2003). The labels assigned by the model are compared with the actual labels of the data. The accuracy is the percentage of data points with labels that are correctly assigned by the model divided by the total amount of data points in the test set and multiplied by 100 (Chang, & Lin, 2013).

The SVM algorithms used for analyzing the measurements of the sensor sock are designed and performed by dr. Z. Di, post-doc at the Eindhoven University of Technology, Eindhoven, the Netherlands. The algorithms are written in Python software (Python Software Foundation, 2019). Due to the large variations in SC data per participant, the data needed to be corrected before running the SVM algorithm. The first deep breathing exercise for each participant was selected as a baseline measurement. This baseline measurement was subtracted from the other data sets. Since the number of measurement samples was too small for an SVM algorithm, the data set was enlarged ten times using a modified synthetic minority over-sampling technique (SMOTE) (Chawla, Bowyer, Hall, & Kegelmeyer, 2002). A 5-fold cross-validation method was used to group the data in test- and training sets. This method divides the data randomly into five sets. Each set is used four times as a training set for the model to obtain the optimal classifier for each task, and one time as the test set to predict the label of each sample. The procedure of the 5-fold cross-validation is repeated 20 times to prevent bias from the fold selection.

Two SVM algorithms were run with the SC data. The first algorithm consists of a two-class classification with the stressor task labeled as ‘positive’ and the relaxation task labeled as ‘negative’. Radial basis function (RBF) kernel was used for the SVM classifier and grid search method was employed to determine the optimal regularization parameters. The second algorithm contains a seven-class classification of the SAM’s arousal scale (see Figure 8.2 for the labels 1 to 7 as applied to the arousal scale). The SVM classifier used RBF kernel and One-vs-One multiclass strategy and determined the optimal regularization parameters by a grid search method. Both classification problems used the same features of the SC data. The feature vector consisted of 3 features: skin resistance data, skin conductance data, and standardized skin conductance data. The sensor sock is considered accurate when the SVM’s accuracy is at least 80%.

8.3 Results

Due to a technical problem with the Bioresponse system, the sensor data from one participant was completely missing and for another participant, the sensor data of one deep breathing and one stressor task were not available for analysis. The partial data was not included in the analysis to prevent unequal representation of the tasks. As a precaution, the data of one participant, who wore the sensor sock over another sock, was excluded from the analysis.

Comparison 1 - First relaxation task and first Stroop color-word task (1-second interval)

For eleven participants, both the mean SC value and the self-reported scores were lower for the relaxation task than for the stressor task, and for one participant, both values were higher for the relaxation task than for the stressor task (Table 8.1). Three participants had a higher SC value for the relaxation task than for the stressor task and for two participants the SC values remained equal; however, all four participants reported lower arousal scores for the relaxation task than for the stressor task. One participant showed a higher mean SC value for the relaxation task than the stressor task, but only reported an arousal score for the stressor task. One participant reported no difference in arousal score, while the mean SC value for the relaxation task was lower than for the stressor task.

Comparison 2 - Second relaxation task and second Stroop color-word task (2-second interval)

For six participants, both the mean SC value and the self-reported scores were lower for the relaxation task than for the stressor task, and for one participant, both values were higher for the relaxation task than for the stressor task (Table 8.1). Five participants reported no difference in arousal scores, while their mean SC values for the relaxation task were lower than for the stressor task. Three participants had a higher SC value for the relaxation task than for the stressor task and for four participants the SC values remained equal; however, all six participants reported lower arousal scores for the relaxation task than for the stressor task.

Participant	Relaxation task 1		Stroop color word 1		Relaxation task 2		Stroop color word 2		Relaxation task 3		Arithmetic task	
	Mean SC	SAM[1]	Mean SC	SAM[1]	Mean SC	SAM[1]	Mean SC	SAM[1]	Mean SC	SAM[1]	Mean SC	SAM[1]
1	0.0031	5	0.0029	4	0.0043	3	0.0048	4	0.0063	5	0.0054	4
2	0.0067	3	0.0072	6	0.0057	4	0.0071	4	0.0082	1	0.0081	7
3	0.0001	4	0.0001	5	0.0001	4	0.0002	5	0.0002	4	0.0001	5
4	0.0038	2	0.0123	4	0.0073	3	0.0116	3	0.0116	2	0.0125	3
5	0.0062	5	0.0060	6	0.0057	5	0.0060	5	0.0057	5	0.0059	6
6	0.0057	4	0.0065	5	0.0056	4	0.0072	4	0.0058	4	0.0059	4
7	0.0076	1	0.0125	7	0.0043	2	0.001	1	0.0046	3	0.0078	7
8	0.0001	3	0.0003	6	0.0003	2	0.0003	3	0.00004	1	0.00004	7
9	0.0004	3	0.0008	5	0.0006	1	0.0005	4	0.0004	2	0.0004	6
10	0.0013	3	0/;.0050	4	0.0008	1	0.0040	3	0.0016	2	0.0038	4
11	0.0026	5	0.0034	7	0.0022	4	0.0027	6	0.0028	4	0.0020	7
12	0.0003	2	0.0004	2	0.0003	4	0.0003	3	0.0003	4	0.0003	4
13	0.0005		0.0003	4	0.0019	3	0.0008	5	0.0017	5	0.0016	2
14	0.0003	4	0,0004	5	0.0004	4	0.0005	5	0.0005	5	0.0005	5
15	0.00002	3	0,00002	7	0.00002	3	0.00002	7	0.00003	3	0.00002	5
16	0.0016	2	0.0015	5	0.0014	1	0.0011	4	0.0006		0.0006	
17	0.0023	3	0.0056	5	0.0034	4	0.0060	4	0.0041	3	0.0056	5
18	0.0057	3	0.0082	7	0.0028	2	0.0065	5	0.0010	2	0.0018	6
19	0.0005	3	0.0001	5	0.0001	3	0.0001	5	0.0001	4	0.0001	3

Note: [1] With SAM, the score on the arousal scale of the SAM questionnaire is meant.

Table 8.1 Participants' mean skin conductance values and SAM arousal scores per activity.

Comparison 3 - Third relaxation task and arithmetic task

For six participants, both the mean SC value and the self-reported scores were lower for the relaxation task than for the stressor task, and for two participants, both values were higher for the relaxation task than for the stressor task (Table 8.1). For six participants the mean SC value remained equal. For two of these participants, the reported arousal score was also equal, for two participants, the arousal score was lower, for one participant, the arousal score was higher, and for one participant no arousal score was reported. One participant reported no difference in arousal scores, while the mean SC value for the relaxation task was lower than for the stressor task. Four participants had a higher SC value for the relaxation task than for the stressor task, however, reported lower arousal scores for the relaxation task than for the stressor task.

Accuracy

Both the t-test comparing the mean SC values ($t = -3.67$, $p = 0.001$) and the t-test comparing the self-reported scores ($t = -7.130$, $p = 0.000$) for the relaxation tasks compared to the stressor tasks, were significant. The SVM two-class classification yielded a mean classification accuracy of 99% with a standard deviation of .02, and the seven-class classification SVM achieved a mean classification accuracy of 95.45% with a standard deviation of .05.

8.4 Discussion

8.4.1 Participants

The accuracy of the Bioresponse system is evaluated with 22 Ph.D. students of the Eindhoven University of Technology, Eindhoven, the Netherlands. The analysis included data of 19 participants. This sample size is quite small to perform an SVM algorithm on. The small sample size was offset by increasing the sample size with the SMOTE method, thereby enabling reliable results from the SVM algorithm. Another limiting factor of the sample is that it was a convenience sample resulting in participants being of one age range (25–35 years) and mostly female (64%).

8.4.2 Evaluation

The Bioresponse system was evaluated with non-disabled participants to verify the stress/emotional arousal measured by the system corresponds to the participant's self-reported experience of stress/emotional arousal. This study has revealed that the Bioresponse system accurately measures the stress/emotional arousal level of the participants. The sensor signal was significantly different for relaxation tasks compared to stressor tasks and could be classified as such with an accuracy of 99%. In comparing the sensor signal to the participant's self-report measure, an accuracy of 95% was achieved.

These accuracy predictions result from a laboratory experiment, where participants were exposed to only two types of situations (relaxation exercises and stressor tasks) in a controlled environment (e.g., the participant was alone in the room without any distracting activities going on). The intended usage of the Bioresponse system is in everyday situations without any control over the environment. The accuracy predictions achieved in this study cannot be transferred to situations outside the controlled environment. The accuracy with which the algorithm can detect stressful situations is specific for the dataset and the context in which the dataset is recorded. The accuracy predictions do, however, prove that the measured stress/emotional arousal corresponds to the experience of the participant.

8.4.3 Study design

Not all the tasks functioned as intended for some of the participants. Two participants indicated that the deep breathing task was stressful for them instead of relaxing (Participants 1 and 5). They also indicated this in the self-reported arousal scores of 5 (except for the second deep relaxation task of participant 1; see Table 8.1). Since the aim of the study was to verify whether the system's measurements correspond to the participant's self-report and both measurement and self-report likely indicated high arousal for these participants, the implication for the result of this study is minimal. However, in future studies that specifically aim to measure relaxation, the deep-breathing task should be replaced with other relaxation exercises. Some participants indicated that the arithmetic task was too difficult, because of the time limit per math exercise. Although becoming stressed at first, some participants 'zoned out' and did not actively participate in the task. Again, given the aim of the study, the implication is expected to be minimal; however, the time per math exercise should be slightly extended for future studies. Other participants indicated that the Stroop color-word test was demanding (meaning the task had a high mental workload), but fun instead of stressful. Since a high mental workload, like stress, is associated with high arousal and the sensor data is compared to the arousal scale of the SAM questionnaire, the results are still in accordance with the aim of the study. For future studies that specifically aim at measuring stress, other stressor tasks than the Stroop color-word task should be considered.

8.5 Conclusion

The Bioresponse system aims at providing professional caregivers with additional cues to support them in their interaction with their clients with S/PID. To be able to support caregivers with additional information, it is vital that this information is accurate. An evaluation with 22 Ph.D. students of the Eindhoven University of Technology has proven that the measurements of the Bioresponse system correspond with the self-reported experience of the participants. The sensor signal was significantly different for relaxation tasks compared to stressor tasks and could be classified as such with an accuracy of 99%. In comparing the sensor signal to the participant's self-report measure, an accuracy of 95% was achieved. Although these accuracy predictions cannot be extrapolated to other test situations, these predictions do show that the additional information the Bioresponse system provides to caregivers is accurate.

Preface

Previous chapters have validated that physiological signals are a valid measure for emotional arousal (based on a study with children with Prader–Willi syndrome in Chapter 3) and that the system can measure arousal accurately (in a study with non-disabled subjects, described in chapter 8). In this chapter, physiological signal monitoring as a measure of (emotional) arousal for persons with visual and severe/profound intellectual disabilities (V-S/PID) is evaluated (addressing research subquestion 1b “Can technologies, developed to measure (emotional) arousal for persons without disabilities, also measure (emotional) arousal for persons with V-S/PID?”) Secondly, this chapter aims to answer research subquestion 2b “What is the relationship between (emotional) arousal as measured by the monitoring system and the (emotional) arousal as observed in the client’s behavior?”

Chapter 9 Validating the sensor measurements of the Bioresponse system with behavioral observations

9.1 Introduction

Persons with intellectual disabilities (ID) are a group that is prone to experiencing stress and may have deficits in coping with stress (Janssen, Schuengel, & Stolk, 2002). Individuals with severe or profound intellectual disabilities (S/PID) are even more prone to stress as a result of additional visual impairments and/or hearing impairments, which are common to occur with S/PID (Evenhuis, Theunissen, Denkers, Verschuure, & Kemme, 2001; Bloeming-Wolbrink et al., 2012). Stress and communicative impairments are known causes for challenging behavior (CB) (Poppes, Van der Putten, & Vlaskamp, 2010). Individuals with S/PID tend to show CB on a daily or weekly basis (Poppes et al., 2010). Janssen and colleagues (2002) created a stress-attachment model in an attempt to explain the occurrence of CB. In their model, they state that the biological response system of individuals with S/PID most likely is in an almost permanent state of activation due to frequently elevated levels of stress. As a result, even small stressful events can cause persons with S/PID to experience high levels of stress. Their way of coping with unpleasant situations may be through using challenging behavior (Lecavalier & Butter, 2010). Frequently elevated levels of stress have serious implications for the individual's wellbeing and health. For persons with S/PID, high levels of stress in combination with challenging behavior have implications for their physical and social development (Poppes et al., 2010; Denis, Van Den Noortgate, & Maes, 2011).

Although the implications of stress are severe, research on stress for persons with ID, and especially persons with S/PID, is limited. Bramston, Fogarty, and Cummins (1999) have studied group-specific stressors for persons with mild or moderate ID using a self-report questionnaire — the Lifestress Inventory. They found that most of the experienced stressors are common for both persons with and without ID, although persons with ID describe more stress from interpersonal relationships compared to the reference group of college students, who reported more work/study-related stressors. One reason for the limited amount of research to stress for persons with S/PID might be their limited communication skills (Smith & Matson, 2010; Adams & Oliver, 2011). They tend to rely on non-verbal communication, using gestures, eye gaze, body language, facial expression, and vocalizations to express themselves (Smith & Matson, 2010; Munde, Vlaskamp, Ruijssenaars, & Nakken, 2009). These expressions exclude self-report as a measure of stress. Informant ratings can be used as a replacement; however, often informant ratings have low convergence with self-report and are, therefore, recommended to be used in combination with self-report (Bramston & Fogarty, 2000; Lunsky & Bramston, 2006).

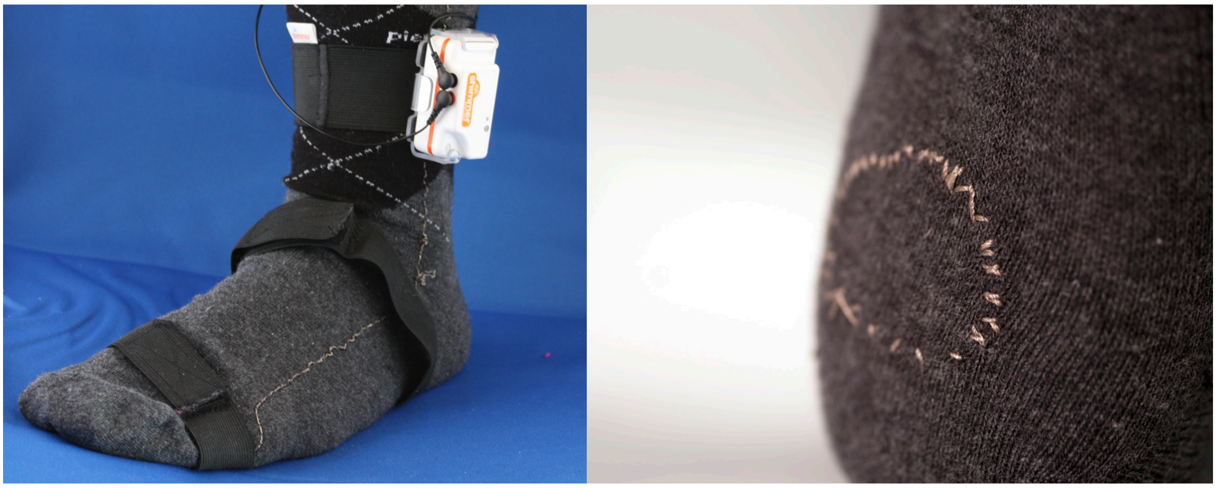


Figure 9.1 Sensor sock.
Panel 9.1A: Sensor sock with a Shimmer 2R Biophysical module.
Panel 9.1B: Integrated fabric electrode (photo: M. Croes).

Although stress measurement of individuals with S/PID through self-report and informant ratings are challenging, physiological measures of stress are still valid. In a study by Sterkenburg, Schuengel, and Janssen (2008), stress levels of a blind client with severe ID were measured during therapy sessions using the VU-AMS ambulatory system for ECG recordings. This study showed that more sensitive and responsive behavior from the therapist resulted in lower levels of stress for the client and reduced the client's display of challenging behavior (Sterkenburg, Schuengel, & Janssen, 2008; Sterkenburg, Janssen, & Schuengel, 2008). Even though Sterkenburg and colleagues were successful in measuring stress for clients with S/PID, the VU-AMS ambulatory system is not suitable for stress measurements in the client's home environment. The VU-AMS system requires a wired connection from electrodes on the client's body to a sensor unit and from this unit to a computer. Next to the limited freedom of movement these wires introduce, wearing the electrodes and the required regular replacement of the electrodes can be uncomfortable.

The Bioresponse system is designed by M. Croes, L. Vork, and P. Peters (Eindhoven University of Technology, Eindhoven, the Netherlands) to measure stress and (emotional) arousal with the use of physiological measures in the client's home environment. The system's sensor sock measures skin resistance (SR) over the client's foot sole with integrated fabric electrodes that are connected to a Shimmer 2R BioPhysical sensor (Shimmer, Dublin, Ireland) (Figure 9.1). The measured SR data is transmitted wirelessly (via Bluetooth) from the Shimmer sensor to a tailor-made Android application. This application visualizes the SR signal in the shape of a flower.

In chapter 8, the accuracy of the Bioresponse system is validated with non-disabled subjects by comparing self-reports of arousal levels to the sensor's measurements. The system has been found accurate in its measurement. In this chapter, the Bioresponse system is compared to behavioral observations of persons with visual and severe/profound intellectual disabilities (V-S/PID) to discover how these observations relate to the sensor's measurements. Section 9.2

describes the methods and materials used in this study. The results of the study are reported in section 9.3 and the discussion is presented in section 9.4. Finally, the conclusion is provided in section 9.5.

9.2 Methods and Materials

9.2.1. Participants

The pilot study was part of the randomized multiple baseline study (described in chapters 10, 11, and 12). Four clients dropped out of this study; however, for two clients the recorded SR data could still be used for analysis. The clients and one of their professional caregivers were initially selected for participation by developmental psychologists from Bartiméus, a Dutch organization providing support for persons with visual and/or intellectual disabilities, together with 10 other client-caregiver dyads. These dyads were selected based on the following inclusion criteria: the client is older than 18 years, has a severe/profound intellectual disability as defined in the client's personal file, has a visual disability as defined in the World Health Organization standards (1980), is able to participate for the duration of the study, and is able to remain seated during the observations. Eight client-caregiver dyads were randomly selected and invited for participation in this study. Written consent for participation was obtained from the caregivers and the client's legal representatives. This study received ethical approval from the Medical Ethical Committee from the Vrije Universiteit medical center, Amsterdam, the Netherlands (reference number: NL53963.029.15).

Client A was a 43-year-old male with severe visual and intellectual disabilities. The professional caregiver who agreed to participate in this study with him had more than 5 years of experience working with persons with visual and/or intellectual disabilities and with client A. Client-caregiver dyad A stopped their participation due to the tasks not matching the caregiver's expectations. Client B was a 52-year-old female with visual and profound intellectual disabilities. The participating caregiver had 3-5 years of experience working with client B and more than 5 years of experience working with persons with visual and/or intellectual disabilities. This client-caregiver dyad's participation was ended due to the tasks being too strenuous for the client.

9.2.2 Procedure

The clients' physiological signals were monitored with the SR sensor sock during three different activities: (1) a structured play moment, (2) a daily care moment, and (3) a semi-structured play moment. In the structured play moment, which was inspired by the Early Social Communication Scale tasks (Mundy et al., 2003), the caregiver and client interacted with three toys (each for 2–3 minutes) and sang songs together (for approximately 2–3 minutes). For the daily care moment, the caregivers selected a common care moment. For client A, this was having lunch and for client B, applying nail polish was selected. The last activity was the Three Boxes procedure (NICHD Early Child Care Research Network, 1999, 2003). In this procedure, the caregiver guides the client through 15 minutes of play, using the toys presented in three bags. The first bag contained a (tactile) reading book, the second bag included a pop-up puppet, and the third bag held a cuddly toy. The caregiver had to divide the time over the three bags as he/she deemed fit, as long as he/she started with bag 1 and finished with bag 3. The toys used in activities one and three were provided by the researchers and, where needed, could be expanded with the client's personal toys. The three tasks for client A were recorded during four days spread over eleven days. The duration of each situation varied from 8 to 11 minutes. For client B, these tasks were recorded for eight days over 1 month. The duration of each situation varied from 7 to 17 minutes. The interactions between caregiver and client were recorded with a video camera.

9.2.3 Instruments

Arousal & Valence Observation Scheme

The Arousal & Valence Observation Scheme was based on the Behavior Signaling Observation List (in Dutch: signaleringsplan). The Behavior Signaling Observation List is developed at Bartiméus, where each client has a personalized list that describes his/her behavior for six (emotional) states: "low alertness", "understimulated", "relaxed", "a little tense", "tense", and "stressed". These states can be described by a combination of arousal and valence. Since the sensor signal cannot distinguish between positive and negative valence, the Arousal & Valence Observation Scheme was created to evaluate the arousal levels measured with the sensor. This scheme has an arousal scale that can vary from "1. very low arousal" to "6. very high arousal" and a valence scale that ranges from "-6. very high negativity" to "6. very high positivity" (see Appendix C, page 204, for the Arousal & Valence Observation Scheme). The author and an independent observer — a master's student Clinical Psychology from the Vrije Universiteit Amsterdam — coded the duration of each arousal and valence score for all videos recorded in this pilot study in random order. The inter-rater agreement between the two coders on the arousal scale was 56.6%.

9.2.4 Analyses

The analysis of the sensor data and behavioral observations consisted of three parts. The first part of the analysis was a visual inspection of both the sensor and observation data. This visual inspection aimed to validate electrodermal activity as a suitable measure of arousal for persons with V-S/PID. For the visual inspection, skin conductance (SC) was used — calculated from the SR data using the formula SC = 1/SR — since SC can be compared more intuitively to the behavioral observations. The behavioral observation scale increases in value when the arousal level increases. SC also increases in value for increasing arousal levels, while SR decreases. For easy comparison, the raw SC data (meaning no filters are applied to the data) and the averaged scores of the arousal scale were plotted in one graph for each measurement.

The second and third parts of the analysis aimed to define the relationship between the sensor data and the behavioral observations. For the second part of the analysis, the averaged scores of the arousal scale are compared to the mean SC value for each score. Therefore, the SC data points were clustered by average arousal scores; meaning all data points with the same label (e.g., an arousal score of 3) were combined into one group. Then, the mean and standard deviation of the SC data points in each cluster were calculated. The hypothesis was that a higher observational score would be reflected in the sensor data by a higher mean SC value.

The last part of the analysis was to calculate the percentage of agreement between the sensor data and the behavioral observations. To calculate the percentage of agreement, the sensor data had to be transformed into an arousal score that uses a similar scale to the behavioral observation scale. The sensor score is an integer between 1 and 6 and is based on the number of standard deviations the SC value is removed from the mean (Table 9.1). Due to the sensor score being an integer, this score cannot be compared to the averaged scores of the arousal scale. Therefore, the percentage of agreement between the sensor score and each observer is calculated first. This percentage of agreement is calculated by dividing the number of data points that have the same value for the sensor score as the behavioral score by the total number of data points and multiplying this result by 100. Finally, the percentages of agreement for each observer are averaged to determine the percentage of agreement between the sensor data and the behavioral observation.

9.3 Results

The data of seven activities were available for analysis. One measurement for each activity could be analyzed for client A. For client B, two measurements for the structured play moment, one measurement for the daily care moment, and one measurement for the Three Boxes procedure were available.

9.3.1 Visual inspection

The two plots for the daily care moment showed a relatively flat SC signal. These measurements also showed little variation in behavioral observation scores (for an example, see Figure 9.2). Three measurements — the structured play moments for clients A and B — showed a fluctuating SC signal together with varying behavioral observation scores (see Figure 9.3 for an example). The plot for client A's Three Boxes procedure displayed a relatively flat SC signal with a short moment of fluctuations near the end of the measurement (Figure 9.4). The behavioral observations, however, were varying throughout the measurement. The plot for the Three Boxes procedure of Client B showed a combination of a flat SC signal and little behavioral observations with a fluctuating SC signal and varying behavioral observations (Figure 9.5).

Sensor score	Skin Conductance value
1	value between 3 SD below the mean and 2 SD below the mean
2	value between 2 SD below the mean and 1 SD below the mean
3	value between 1 SD below the mean and the mean
4	value between the mean and 1 SD above the mean
5	value between 1 SD above the mean and 2 SD above the mean
6	value between 2 SD above the mean and 3 SD above the mean

Note: SD = standard deviation.

Table 9.1 Assigning sensor scores based on the skin conductance value

From the start to the end of the measurement, the SC signal had a steady decline for client A's structured play moment and a slight decline for client A's daily care moment (Figure 9.2) and Three Boxes procedure (Figure 9.4). In client B's plots of the structured play moments and daily care moment, the SC signal showed a steady increase from the start to the end of the measurements (for an example see Figure 9.3). However, this steady decline or increase in the SC signal was not reflected in the behavioral observation scores, which varied between an arousal score of 2 to 3.5 with an occasional peak of an arousal score of 4. For client B's Three Boxes procedure the SC signal starts with a steady decline, which was also reflected in the behavioral observation scores, which drops from arousal scores of 3 to 3.5 to scores of 2 to 2.5. From halfway through the measurement to the end, the SC signal showed a steady incline again. This, however, was not reflected in the behavioral observation scores, which varied from scores of 2 to 3 with occasional peaks to a score of 3.5.

9.3.2 Mean skin conductance values

For each measurement, the mean and standard deviation per observation score on the arousal scale was calculated (Table 9.2). None of the measurements showed a consistent increase in mean SC value for consecutive observer scores. For client A, the consecutive observer scores show an increasing trend in mean SC value except for observer score 3 in the structured play moment, observer score 4 in the daily care moment, and observer scores 2.5 and 4 for the Three Boxes procedure (Figure 9.6). For client B's structured play moments and daily care moment, the mean SC values have a decreasing trend for consecutive observer scores. The Three Boxes procedure from client B had an almost equal mean SC value for observer scores 1 and 1.5, had a steep increase from observer score 1.5 to 2, and then slightly decreased from observer scores 2 to 3.5 (Figure 9.6).

9.3.3 Comparing sensor values with behavioral observation

For the independent observer, the percentage of agreement between the sensor score and the observation score of the arousal scale, averaged over all measurements, was 31.8% with a range

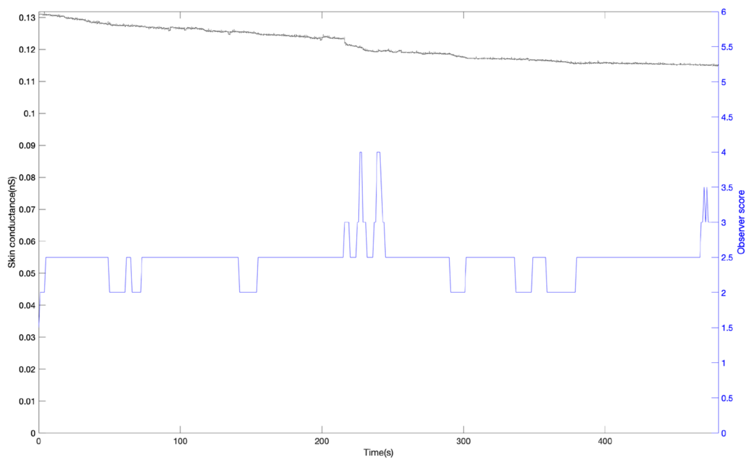


Figure 9.2 Skin conductance signal (black) and behavioral scores for the arousal scale (blue) for Client A's daily care moment.

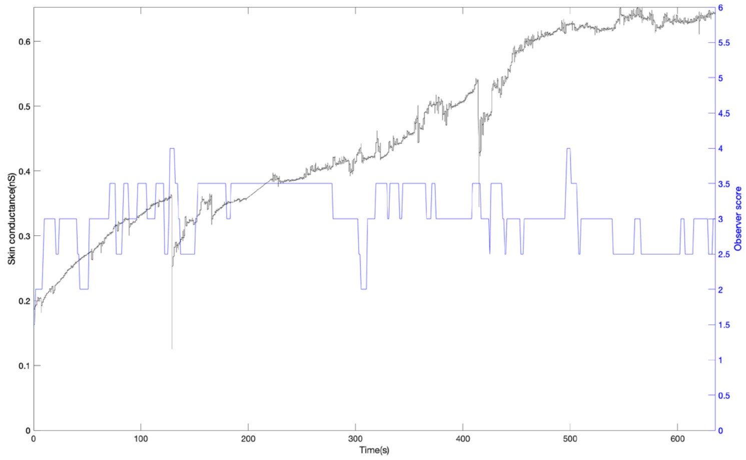


Figure 9.3 Skin conductance signal (black) and behavioral scores for the arousal scale (blue) for Client B's second structured play moment.

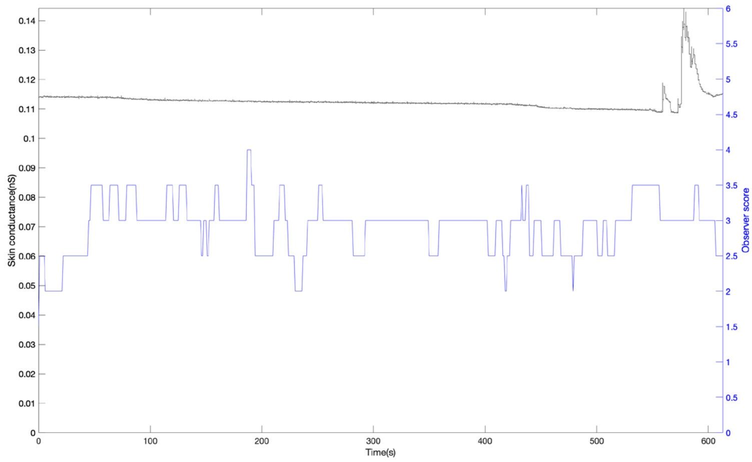


Figure 9.4 Skin conductance signal (black) and behavioral scores for the arousal scale (blue) for Client A's Three Boxes procedure.

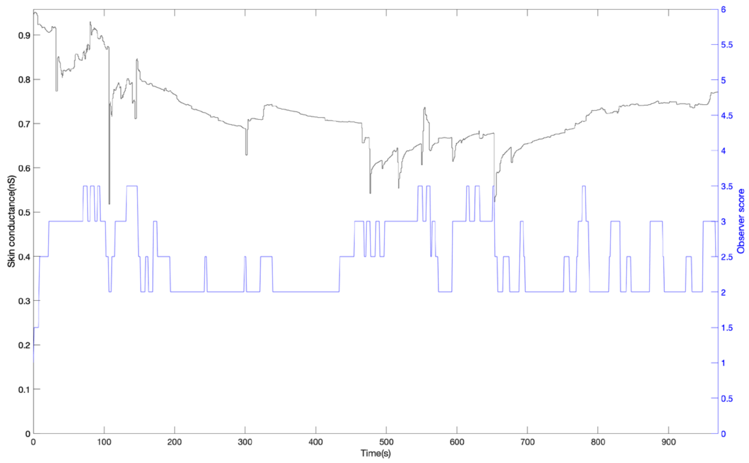


Figure 9.5 Skin conductance signal (black) and behavioral scores for the arousal scale (blue) for Client B's Three Boxes procedure.

Client	Measurement		Total	Observer scores 1	1.5	2	2.5	3	3.5	4	4.5	5	5.5	6
A	Structured play moment	Number of data points	25650	0	51	1179	10242	9010	2609	2559	0	0	0	0
		Mean	0.457	-	0.001	0.432	0.462	0.351	0.623	0.662	-	-	-	-
		Standard deviation	0.237	-	0.001	0.126	0.246	0.209	0.153	0.152	-	-	-	-
A	Daily care moment	Number of data points	24627	0	51	4100	18838	1228	153	257	0	0	0	0
		Mean	0.878	-	0.799	0.877	0.876	0.906	0.919	0.888	-	-	-	-
		Standard deviation	0.043	-	0.001	0.045	0.043	0.026	0.019	0.005	-	-	-	-
A	Three Boxes procedure	Number of data points	31437	0	51	1332	7382	17861	4606	205	0	0	0	0
		Mean	0.958	-	0.942	0.951	0.964	0.957	0.959	0.958	-	-	-	-
		Standard deviation	0.030	-	0.001	0.011	0.015	0.035	0.028	0.001	-	-	-	-
B	1st Structured play moment	Number of data points	33948	0	0	5858	7149	19306	1635	0	0	0	0	0
		Mean	0.095	-	-	0.108	0.104	0.090	0.073	-	-	-	-	-
		Standard deviation	0.088	-	-	0.107	0.085	0.085	0.020	-	-	-	-	-
B	2nd Structured play moment	Number of data points	31353	0	102	1121	5569	13786	10296	479	0	0	0	0
		Mean	0.213	-	0.590	0.388	0.171	0.203	0.226	0.244	-	-	-	-
		Standard deviation	0.108	-	0.009	0.134	0.106	0.114	0.053	0.151	-	-	-	-
B	Daily care moment	Number of data points	24073	0	60	18190	4699	1124	0	0	0	0	0	0
		Mean	0.061	-	0.101	0.063	0.057	0.027	-	-	-	-	-	-
		Standard deviation	0.030	-	0.001	0.029	0.033	0.004	-	-	-	-	-	-
B	Three Boxes procedure	Number of data points	49715	51	358	23218	8364	14437	3287	0	0	0	0	0
		Mean	0.081	0.038	0.038	0.082	0.081	0.081	0.077	-	-	-	-	-
		Standard deviation	0.019	0.000	0.002	0.011	0.022	0.022	0.033	-	-	-	-	-

Note: Mean and standard deviations are calculated over skin conductance values and reported in nS.
The sensor collected 51 data points per second.

Table 9.2 Mean and standard deviation of skin conductance values calculated per averaged arousal scores from 15.3% to 56.9%. For the author, the percentage of agreement between the sensor score and the observation score of the arousal scale, averaged over all measurements, was 33% with a range from 14.2% to 59.1%. The average percentage of agreement between the sensor score

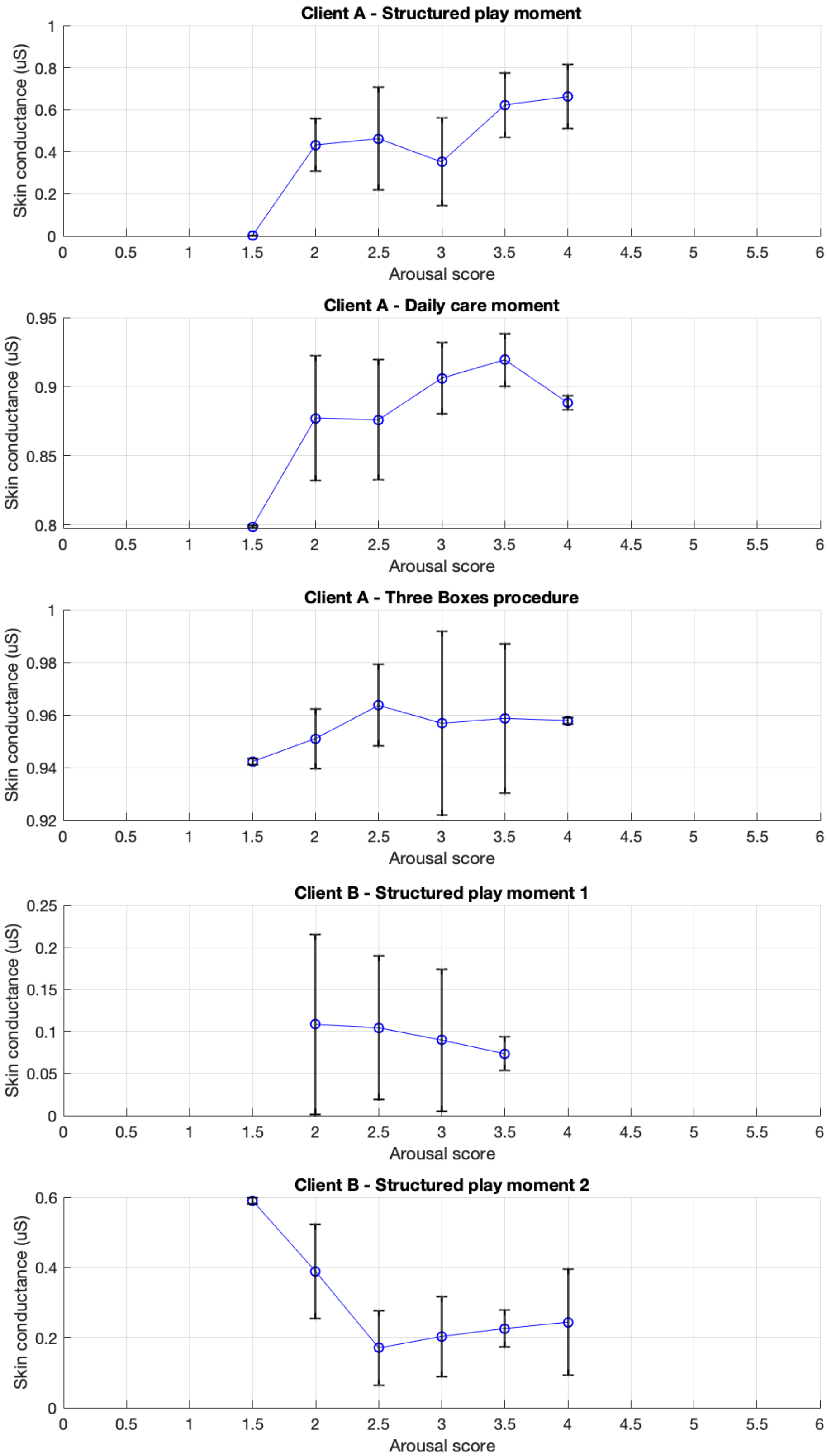


Figure 9.6 Mean skin conductance (blue) and standard deviation (black) for each arousal score.

and the observation score of the arousal scale, averaged over all measurements, was 32.4% with a range from 14.8% to 58%.

9.4 Discussion

The pilot study has evaluated the relationship between the behavioral observations of persons with V-S/PID and the sensor's measurements. This pilot study has found an average agreement between the behavioral observations and the sensor's measurements of 32.4%. The mean skin conductance values did not consistently increase over the arousal levels used in the behavioral observation. In three situations for client B, the mean values did even decrease for increasing arousal levels, and in one situation a fluctuation in mean values was observed for increasing arousal levels. Visual inspection of the SC data has shown that a graph with few fluctuations generally corresponds to a low number of observed changes in the client's behavior; while a graph with frequent fluctuations relates to frequently observed changes in the client's behavior. The majority of the graphs displayed a steady increase or decrease in the SC signal from the start to the end of the measurement. Overall, this increase/decrease could not be seen in the arousal scores from the behavioral observation, which tended to continuously fluctuate between the middle values (scores 2 to 4).

Due to the small sample of participants and the low number of measurements in this pilot study, the results cannot be generalized to other clients. The sample was also a convenience sample as the results from the participants who dropped out of the randomized multiple baseline study (more information on this study is described in chapters 10, 11, and 12) were used. However, this pilot study was still able to provide insights into the relationship between the behavioral observations and the sensor's measurements.

The agreement between behavioral observations and the sensor's measurements is low.

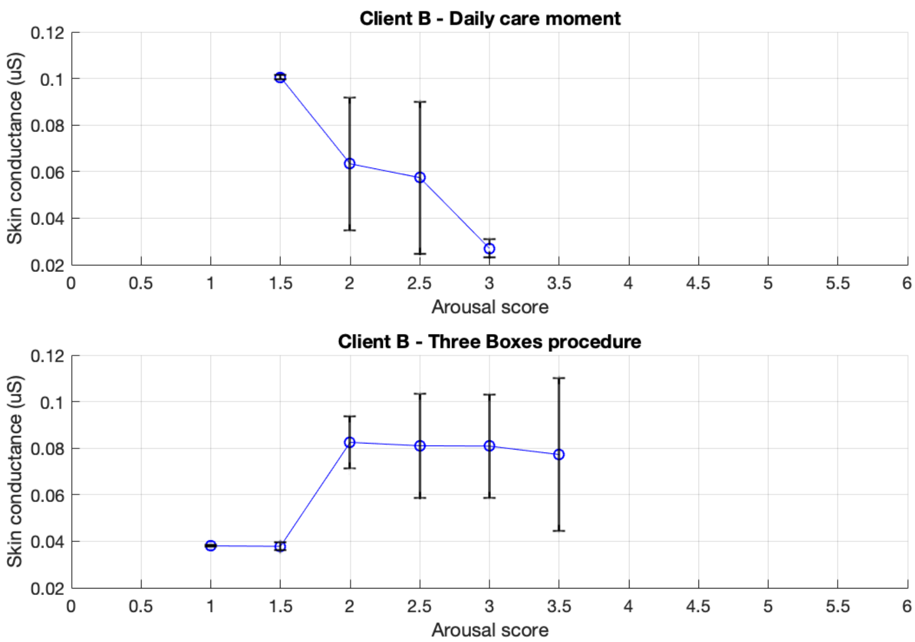


Figure 9.6 Continued Mean skin conductance (blue) and standard deviation (black) for each arousal score.

This might be due to the subtle communicative signals persons with V-S/PID use to express their needs, wishes, and emotions. As stated in the problem statement (Chapter 1, page 2), caregivers have to rely on behavioral observations to interpret their client's communication, which is challenging to interpret as it is mostly non-verbal. Research has shown that behavioral observation can be reliable to interpret emotions, but also that observations can differ largely between caregivers and that the interpretation may depend on the context wherein this behavior is shown (Vos, De Cock, Petry, Van Den Noortgate, & Maes, 2013). The Bioresponse system is specifically developed to support this interpretation; and yet, the analysis to determine the agreement between behavioral observations and the sensor's measurements takes the behavioral observation as the golden standard. Since the use of verbal or written self-reports is not possible, behavioral observation is the best comparison available. Research with other target groups (e.g., non-disabled subjects, like the study reported in chapter 8) is required to gain more insight into the accuracy and interpretation of the physiological data.

Another contributing problem may be the selection of the measurement situations. Previous studies from Vos et al. (2012, 2013), Lima, Silva, Amaral, Magalhães, and de Sousa (2013), and Lima et al. (2012) selected situations that were known to be pleasant or unpleasant to the participant or they selected stimuli that were bound to trigger a reaction; meanwhile, interfering stimuli were removed where possible. The current study intended to examine the use of the Bioresponse system in the daily environment; therefore, the presence of interfering stimuli was not prevented. The selected situations were either from standardized methods or from daily situations encountered in the client's environment. As a result, little variation in arousal was observed in both the sensor measurements and the behavioral observation. A study from Vandesande et al. (2020) compared the arousal levels of children with profound multiple intellectual disabilities between a situation where the child was comforted by a stranger to being comforted by the parent. Arousal was measured by the Bioresponse system and by behavioral observation. A high correlation between the measurements of the Bioresponse system and the behavioral observations was found. The study from Vandesande et al. (2020) has shown that the Bioresponse system is accurate in situations where a change from low to high arousal, or vice versa, is expected. Future research is required to be able to better interpret the physiological data and the situation's influence on the physiological data. This deeper knowledge may support caregivers in their decision when and how to use the Bioresponse system.

9.5 Conclusion

The Bioresponse system was specifically developed to support professional caregivers in the interpretation of their client's communicative signals. An evaluation with 2 adults with visual and severe/profound intellectual disabilities (V-S/PID) and one of their caregivers has compared the sensor measurements of the Bioresponse system to behavioral observations. An average agreement of 32.4% was found. As the challenges to interpret the client's subtle communicative behavior are the reason for the development of the Bioresponse system, a low agreement is to be expected. This pilot study has highlighted the need for future research to better understand and interpret the physiological data; especially when this data is measured in the daily environment of persons with V-S/PID.

Preface

The Bioresponse system is developed to support (professional) caregivers in their interaction with persons with visual and severe/profound intellectual disabilities (V-S/PID). The system measures physiological signals and visualizes these signals in a tailor-made application. In previous chapters, the use of physiological signals as a measure of arousal has been evaluated (chapters 3 and 9) and found suitable. Also, the accuracy of the system's measurements (chapter 8) and its relationship to behavioral observations (chapter 9) are validated. However, the user experience of the Bioresponse system has so far not been examined. This chapter aims to answer research subquestion 2c "What is the social validity of the monitoring system for professional caregivers?" by gathering the caregiver's opinions on the Bioresponse system.

Chapter 10 Evaluating the social validity of the Bioresponse system with professional caregivers

10.1 Introduction

Technology is becoming more and more integrated, making the products that surround us smarter. A casting device can connect all devices in the home that have access to WiFi (computers, tablets, smartphones, speakers, televisions, etc.), and operate those devices by voice control. There are mobile applications that control the light settings in the room and can open or close the curtains. Even the washing machine comes with a mobile app to operate it from a distance. This integrated technology not only offers ease of use but can also offer a more independent life to people who are dependent on support from others. Elderly can live independently for longer with the help of common smart home technologies such as movement trackers, fall detectors, reminder devices, appliance safety sensors, and hands-free remote controls (Morris et al, 2013).

For persons with intellectual disabilities (ID), smart devices could promote independence, productivity, social functioning (Woensdregt, D'Addabbo, Scholten, van Alfen, & Sterkenburg, 2020), and learning. Augmentative and alternative communication (AAC) devices have emerged to provide persons with communication impairments and motoric disabilities with a means to express their wishes (Lancioni, Singh, O'Reilly, Sigafoos, & Oliva, 2014). One common AAC device is a microswitch — a sensor that is activated with a simple movement and allows its user to control environmental stimuli, such as music, photos, videos, sounds, or lights. Speech-generating devices provide a pre–recorded request for attention or a specific item and can generally be activated by pressing a picture of this item (Lancioni et al., 2014).

Next to smart devices, apps — specifically intended for persons with ID and their family or professional caregivers — are being developed. The app "You and I" is an example of an app that uses serious gaming to support learning (in this case mentalization abilities) for persons with a mild to borderline ID (Derks, van Wijngaarden, Wouda, Schuengel, & Sterkenburg, 2019). Other apps aim for low cost and easily accessible learning for (professional) caregivers, covering topics like empathy in "World of Empa" (Sterkenburg & Vacaru, 2018) and sensitive responsiveness in "Hi-Sense" (van Wingerden, Wouda, & Sterkenburg, 2019).

In their review of AAC technologies, Light and McNaughton (2013) observed an increase in technological innovation in AAC devices; however, they also noticed that this innovation did not result in devices that are adapted to the needs and skills of the persons who depend on those technologies. Woensdregt and colleagues (2020) studied what sensor technologies are desired for clients with visual or visual-and-intellectual disabilities by interviewing experts, care professionals, client representatives, and managers. In order of importance, the results

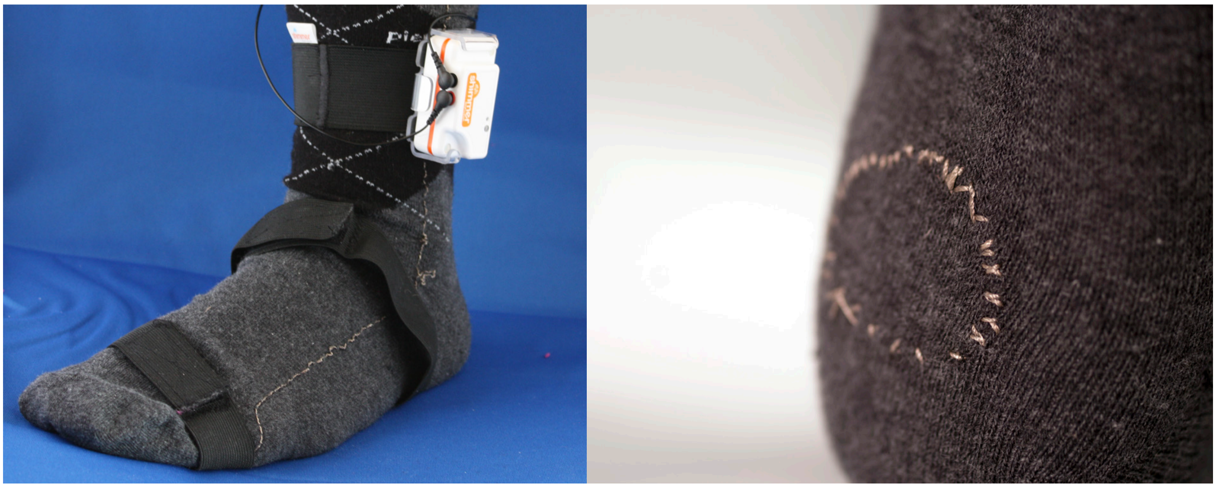


Figure 10.1 Sensor sock.
Panel 10.1A: Sensor sock with a Shimmer 2R Biophysical module.
Panel 10.1B: Integrated fabric electrode (photo: M. Croes).

were: understanding the client's behavior, orientation and localization, health, activation and entertainment, danger prevention, fall detection, control lighting settings, posture, and sleep. This study also identified some requirements for and concerns with sensor technologies. The first concern was intrusiveness. Not all clients tolerate sensor technologies on their bodies since they do not understand what it is for. Other technologies are simply too large to be comfortable. The second concern was reliability. Some sensor technologies are not reliable when used for persons with visual or visual-and-intellectual disabilities (e.g., the person not understanding he/she has to remain still for a measurement to be accurate). Finally, there were some ethical concerns with respect to guarding the client's privacy: who has access to and who has control over the client's data. Regarding the requirements, ease of use and easy to understand output were mentioned (Woensdregt et al., 2020).

The Bioresponse system was developed by M. Croes, L. Vork, and P. Peters (Eindhoven University of Technology, Eindhoven, the Netherlands) to support professional caregivers in better noticing, interpreting, and understanding their client's communicative signals. The system visualizes a physiological measure — skin resistance (SR) — in a tailor-made Android application (app) to provide caregivers with additional cues on the client's behavior since physiological measures can reflect general arousal levels. The SR signal is measured in an unobtrusive manner by integrating fabric electrodes into a sensor sock (Figure 10.1A). These electrodes are connected to a Shimmer 2R BioPhysical sensor (Shimmer, Dublin, Ireland) that transmits the SR data wirelessly (via Bluetooth) to the app (Figure 10.2).

The SR signal is visualized in the shape of a flower. An increasing size of the flower means an increasing SR amplitude, which reflects a decreasing general arousal level. When the flower's size decreases, a decrease in the SR signal is measured that reflects increasing general arousal levels. Additional (orange) flower petals become more visible when an increasing number of small peaks are measured in the SR signal. These small peaks reflect the client's reactions to stimuli in the environment, such as hearing one's name. The additional flower petals' visibility

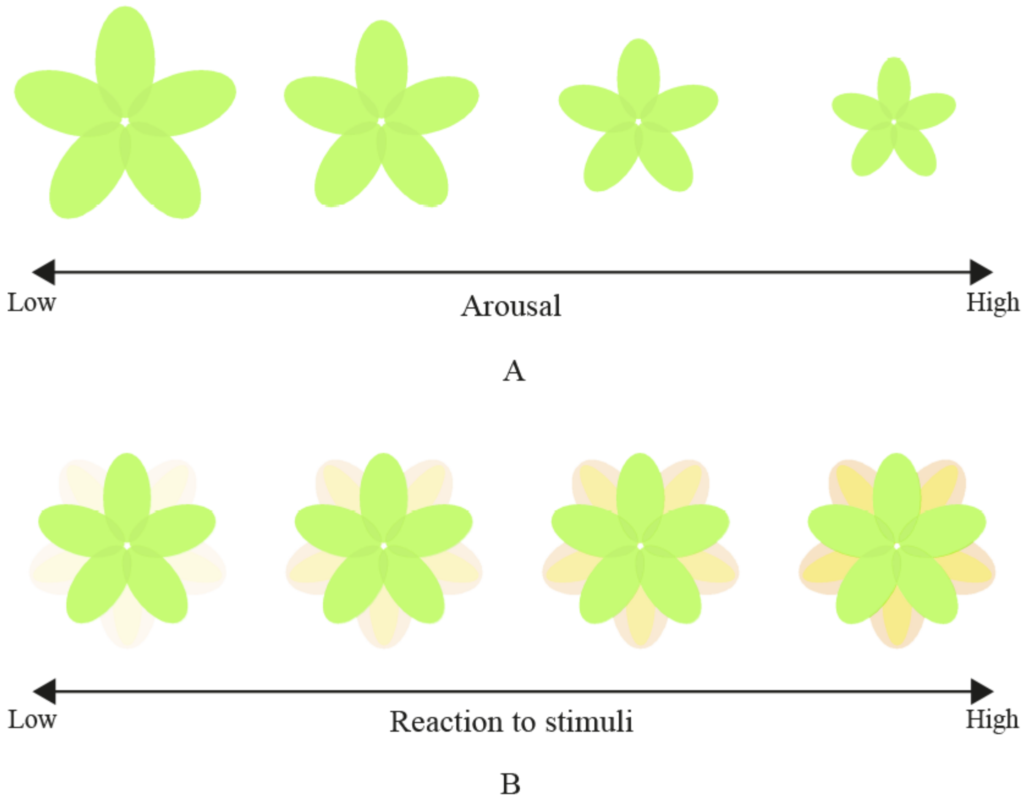


Figure 10.2 The visualization of the flower in the Flower app.
Panel 10.2A: The flower's size decreases when the arousal level increases, and vice versa.
Panel 10.2B: The additional flower petals become more visible if the reaction to stimuli becomes stronger.

decreases when the number of peaks in the SR signal decreases. Next to the flower, six colored buttons are displayed. Caregivers can use these buttons to record their observations of the client's behavior. The colors of these buttons match the "signaling list" (in Dutch: signaleringsplan), a tool to support the interpretation of the client's behavior (purple = "low alertness"; blue = "understimulated"; green = "relaxed"; yellow = "a little tense"; orange = "tense"; red = "stressed").

The Bioresponse system has attempted to fulfill the need for understanding the client's behavior better with unobtrusive measurements and a simple, yet pleasant output. However, the success and acceptance of technology depend on its fit to the user's needs, wishes, and skills (Light & McNaughton, 2013). Frustration in operating a system and lack of training and support for the system are the main reasons for abandoning the technology. In this chapter, the social validity of the Bioresponse system is evaluated with professional caregivers of clients with visual and severe/profound intellectual disabilities (V-S/PID). In section 10.2, the methods and materials used for the evaluation are described. Section 10.3 reports on the results of the evaluation and section 10.4 provides a discussion on the results and limitations of the evaluation. Lessons learned are addressed in section 10.5 and conclusions are drawn in section 10.6.

10.2 Methods and Materials

The Bioresponse system is evaluated with four professional caregivers of adults with visual and severe/profound intellectual disabilities (V-S/PID). The evaluation aimed at validating the usability of the sensor sock and the Flower app in an institutional environment. The usability test was part of a randomized multiple baseline study to evaluate the effects of the Bioresponse system on the interaction between professional caregivers and adults with V-S/PID. The results of this effect study are described in Chapters 11 and 12.

10.2.1 Participants

Four professional caregivers from two Dutch organizations that provide support and care for persons with visual and/or intellectual disabilities, Bartiméus (n=2) and Royal Dutch Visio (n=2), participated in the usability test. They participated in this study together with a client they knew well. These client-caregiver dyads were randomly selected from a list of 12 client-caregiver dyads. This list was composed by the developmental psychologists of both organizations based on the client meeting the study's inclusion criteria (for detailed information on the inclusion criteria, please see Chapter 11, page 131 or Chapter 12, page 147). Although eight client-caregiver dyads have started the randomized multiple baseline study, only four dyads were able to complete the study. The other client-caregiver dyads were unable to complete the study due to the client's resistance to the strap of the Shimmer module, due to the tasks overcharging the client, or due to the tasks not meeting the caregiver's expectations. Due to time constraints or another dyad from the same residence already participating, the remaining dyads on the list could not be included in the study. The caregivers provided written consent for participation, and the Medical Ethical Committee of the Vrije Universiteit medical center, Amsterdam, the Netherlands, approved the study (reference number: NL53963.029.15).

The caregivers were from the age categories: 22–25, 31–40, 41–50, and 51–60. Three of the caregivers were female. All caregivers had more than five years of experience working with adults with V-S/PID. The dyads knew each other well (three knew each other for more than five years and one dyad for 1 to 2 years). Three caregivers completed secondary vocational education, and one caregiver finished higher professional education (for an explanation of the Dutch educational system, please see https://www.government.nl/topics/secondary-vocational-education-mbo-and-higher-education).

10.2.2 Procedure

The participants received a short (1 hour) training on the use of the Bioresponse system and the interpretation of the Flower app, during which ample opportunity to ask questions was provided. After the training, caregivers received a printed manual (see Appendix B, page 186) and a DVD with video instructions on the use and interpretation of the Bioresponse system. The participants then used the Bioresponse system for three months during care moments of the participant's selection. Caregivers were encouraged to use the Bioresponse system for 90 minutes during each shift they worked with the participating client. During this three-month period, the caregivers participated in seven measurements (more explanation on and the results of the measurements are provided in Chapters 11 and 12). After completing the first measurement, the researcher present informed whether caregivers had any questions or concerns regarding the use of the Bioresponse system, and provided additional information where needed.

10.2.3 Instruments

Social validity Scale

The Social Validity Scale (Seys, 1987) is a questionnaire with open-ended questions using 5-point Likert-type ratings to describe the system's desirability, applicability, clarity, efficiency, and burden on daily care. The scale has been adapted to fit the intervention with the Bioresponse system. Caregivers filled out the Social Validity Scale at the start of the study (t0) and directly after the period of three months during which the caregivers could use the Bioresponse system (t1). The t1-questionnaire had one additional question that informed whether the caregivers would participate again in a similar study based on their current experiences.

10.2.4 Analysis

The questions in the Social Validity Scale that concern the randomized multiple baseline study rather than the Bioresponse system specifically are excluded from this analysis (10 questions). The remaining questions are divided into four categories: 1) Perception of the Bioresponse system (4 questions), 2) Training on the use and interpretation of the Bioresponse system (5 questions), 3) Use of the Bioresponse system (8 questions), and 4) Caregivers' perception on changes in their behavior towards the client (14 questions). A Wilcoxon Signed Rank Test explored whether the caregiver's expectations of the Bioresponse system (t0) were significantly different ($\alpha = 0.05$) from their experience with the system (t1). The non-parametric variant of the paired t-test (the Wilcoxon Signed Rank Test) was selected since the Social Validity Scale consists of Likert-scale questions, which is ordinal data. The Wilcoxon Signed Rank Test was performed on the data from each caregiver separately. The combined results of the four caregivers were explored in a meta-analysis, following the method of de Weerth and van Geert (2002). This meta-analysis summed the natural logarithms of each p-value and multiplied the sum by -2. P-values smaller than .005 were substituted for a value of .01, and for changes in unexpected directions, a value of .5 was used instead of the actual value. The combined results followed a chi-squared distribution (with degrees of freedom = 2 * number of cases).

10

10.3 Results

For caregiver D, 50% of the questions of categories 1 and 3, and 100% of the questions of category 4 were left blank in the t0 questionnaire; therefore, the results for categories 1 and 3 need to be interpreted with care. Category 4 for client D is excluded from the analysis. The mean score of Category 1 "perception of the Bioresponse system" increased for caregivers B and C; however, decreased for caregivers A and D. For category 2 "training in the use and interpretation of the Bioresponse system", the mean scores increased for caregivers B and D and decreased for caregivers A and C. The mean scores for category 3 "use of the Bioresponse system" and category 4 "caregivers' perception on changes in their behavior towards the client" decreased from t0 to t1 for all caregivers (Table 10.1).

For caregiver A, the results were significantly different between t0 and t1 for category 3 and 4, and for caregiver C, the results for category 2 differed significantly (Table 10.2). Category 4 was also significantly different in the meta-analysis, even with the corrected p-value for caregiver A

Category	Caregiver	t0		t1	
		Mean (SD)	Missing questions	Mean (SD)	Missing questions
Category 1: Perception of the Bioresponse system	Caregiver A	2.75 (2.06)	0/4	2.67 (1.16)	1/4
	Caregiver B	3.25 (1.50)	0/4	3.50 (1.00)	0/4
	Caregiver C	2.75 (1.50)	0/4	3.33 (1.16)	1/4
	Caregiver D	5.00 (0.00)	2/4	3.00 (1.83)	0/4
Category 2: Training on the use and interpretation of the Bioresponse system	Caregiver A	3.60 (0.89)	0/5	3.20 (0.45)	0/5
	Caregiver B	4.20 (1.30)	0/5	4.60 (0.55)	0/5
	Caregiver C	5.00 (0.00)	0/5	3.80 (0.45)	0/5
	Caregiver D	3.80 (0.84)	0/5	4.20 (0.45)	0/5
Category 3: Use of the Bioresponse system	Caregiver A	3.50 (0.54)	0/8	2.50 (0.54)	0/8
	Caregiver B	3.50 (0.76)	0/8	3.25 (0.71)	0/8
	Caregiver C	2.88 (0.79)	0/8	2.75 (0.46)	0/8
	Caregiver D	4.00 (0.00)	4/8	3.75 (0.71)	0/8
Category 4: Caregivers' perception on changes in their behavior towards the client	Caregiver A	3.79 (0.43)	0/14	2.86 (0.41)	0/14
	Caregiver B	3.43 (0.65)	0/14	3.07 (0.27)	0/14
	Caregiver C	3.18 (0.41)	3/14	3.00 (0.00)	6/14
	Caregiver D	0.00 (0.00)	14/14	3.31 (0.48)	1/14

Table 10.1 Average category score per Social Validity Scale questionnaire (t0 and t1)

(the value .000 was replaced with a value of .01).

Conversations with caregivers during the study have added more insight into the caregiver's perceptions of the usability and clarity of the Bioresponse system. After having used the Bioresponse system for a couple of weeks, one caregiver asked for a repetition of the flower's explanation, due to feeling confused about the meaning of the different flower petals. A caregiver, who was not participating in the study, interpreted the color of the flower to reflect "relaxation," due to the close resemblance of the flower's color with the color of the green button (which represents "relaxation"). The caregiver said to the client: "O, I see you are enjoying your lunch. I can see a green flower." In a conversation with one of the participating caregivers, the lack of variation in the flower's size was mentioned. The caregiver indicated that she had expected more variations in the flower's size, which she had hoped would support her in understanding the client's more subtle communicative behavior.

10.4 Discussion

10.4.1 Participants

The Bioresponse system was evaluated with four professional caregivers of clients with visual and severe/profound intellectual disabilities. This sample size is too small to draw generalized conclusions, but the participants have provided valuable insights for the design of a monitoring system in the institutional context. Due to the relatively small number of persons with EMB in the

Category		Caregiver A	Caregiver B	Caregiver C	Caregiver D		Combined
Category 1: Perception of the Bioresponse system	Z	-1.41	-0.58	-1.00	-1.00	χ^2	9.44
	p	0.16	0.56	0.32	0.32	df	8
						p	> 0.25
Category 2: Training on the use and interpretation of the Bioresponse system	Z	-1.00	-0.82	-2.12	-1.41	χ^2	14.53
	p	0.32	0.41	0.03	0.16	df	8
						p	> 0.05
Category 3: Use of the Bioresponse system	Z	-2.27	-0.54	-0.55	-1,732	χ^2	14.67
	p	0.02	0.59	0.58	0.08	df	8
						p	> 0.05
Category 4: Caregivers' perception on changes in their behavior towards the client	Z	-3.24	-1.89	-1.41	-	χ^2	18.57
	p	0.00	0.06	0.16	-	df	6
						p	< 0.05

Table 10.2 Wilcoxon Signed Ranks Test and meta-analysis (four clients combined) results of comparing the t0 and t1 questionnaire

Netherlands, they — and their caregivers — can be overcharged with requests for participation in studies; therefore, small samples are more common in this area of research. However, the inclusion of a larger sample to validate the Bioresponse system would be preferable in future studies to draw more generalizable conclusions.

10.4.2 Evaluation

The caregiver's perception of the Bioresponse system was obtained through a questionnaire: the Social Validity Scale. The questionnaire results suggest that although the usage of the Bioresponse system did not live up to the caregiver's expectations, two out of four caregivers had a higher mean score for the perception of the Bioresponse system category after using the system. This might indicate that caregivers regard the concept of the Bioresponse system positively. Given the low number of questions per category and the high number of missing questions, the interpretation of the results should be treated with care. The development of the Bioresponse system could have benefitted from an in-depth interview or a co-creation process involving the caregivers in the development. A more in-depth measure could have given more insight into the exact nature of problems with the Bioresponse system and offer more opportunities for caregivers to express their experiences with the Bioresponse system. Due to the Social Validity Scale being part of the randomized multiple baseline study and the high amount of time and effort required for this randomized multiple baseline study, the decision was made to not increase the time and effort of caregivers with time-intensive methods, like in-depth interviews or co-creation processes. Future developments of the Bioresponse system should consider more involvement of caregivers and even clients in the process. The caregivers' feedback, gained through the Social Validity Scale and conversations with caregivers, is used in a redesign of the Bioresponse system (as described in chapter 5, page 60)

10.4.3 The Bioresponse system

After concluding the data collection, the discovery that the feedback in the app (the flower) reflected skin resistance (SR) instead of skin conductance (SC), was made. The training on the interpretation of the Bioresponse system had indicated that increasing arousal levels result in an increasing flower size. While in actuality, an increasing flower size meant a decreasing arousal level. The other way around when caregivers observed a decreasing flower size, they were instructed to interpret this as decreasing arousal levels, while it should be interpreted as increasing arousal levels. This reversed behavior of the flower could potentially lead to the misinterpretation of the client's communicative behavior. Due to a secondary technical problem with the Flower app — the flower did not change in size, although it should have changed given the sensor's measurements — no misinterpretations occurred. However, both technical errors have altered the caregiver's experience of the Bioresponse system and therefore, have influenced the results of this study. No conclusions can be drawn from the results, but valuable feedback for future development of the Bioresponse system has been gained in this study.

10.5 Lessons learned

Although the intervention did not work as intended, the randomized multiple baseline study has provided the chance to use the Bioresponse system for an extended period of time in the context of care organizations. This opportunity has provided insights relevant for both research and design involving the Bioresponse system. The first insight was that walking on the sensor sock distorts the SR measurements since walking frequently alters the pressure applied to the fabric electrodes integrated into the sensor sock (for more information on this problem with the sock design, see chapter 5, page 59). Secondly, a low battery for the tablet PC (lower than 20%) and/or the Shimmer sensor resulted in a weak Bluetooth connection between the tablet PC and the sensor and eventually caused losing the connection entirely. Consequently, caregivers had to schedule the use and charging of the Bioresponse system's devices. Another insight was that recording the sensor's measurements for longer periods (two hours or longer) generated large data files. Since the Flower app reads in and adds to the data in real-time, large data files slowed the process down and reduced the number of recorded data points from 51 to as low as 5 data points per second. These three insights were gained and addressed during the study. The app was altered to create a new file every hour so that the number of data points recorded per second remains constant. Caregivers were informed to check the tablet's and sensor's charge before using the system for optimal results and the study's protocol was altered to pause the activity when the client was walking and to only be resumed when the client was seated again.

Other insights from the current study are relevant for future research, specifically for the training. Training might be more beneficial if it is provided in two separate sessions. The goal for the first session is to cover the usage of the Bioresponse system and the interpretation of the feedback. Caregivers could use the Bioresponse system in between sessions, allowing for addressing questions caregivers encountered while using the system, discussing potential problems and troubleshooting, and for reinforcing the most important topics of the first session. Furthermore, supplementing materials are important to support caregivers. Although, supplementing materials (the printed manual and instruction DVD) were provided in the current study, these materials were not easily accessible enough. The manual took too long to read and was often not stored along with the system to prevent losing the manual. The DVD required the availability of a device able to play the DVD and took too many steps before being able to play the instructions. Future studies should include materials that are easy and quick to use, like a one-page instruction sheet and/or short videos (1 to 3 minutes), that are easily accessible online or preinstalled on the Bioresponse system's device (e.g., the tablet PC).

10.6 Conclusion

The Bioresponse system aims at providing professional caregivers with additional cues to support them in their interaction with their clients with EMB. This monitoring system measured the client's arousal level with a skin resistance sensor integrated into a sock and communicated the measured skin resistance to caregivers by means of an app. The evaluation with four caregivers has uncovered valuable insights for the research and design of the Bioresponse system. The visualization in the shape of a flower lacks some clarity and did not reflect as much variation in the SR signal as the caregivers had hoped. Also, the training and the supplementing materials should be improved. The Bioresponse system needs further development of both the sensor sock and the Flower app to offer a more user-friendly system suitable for the institutional environment, but seems to already receive positive reactions from caregivers.

Preface

The aim for developing a monitoring system was to provide (professional) caregivers with a tool that supports them in their interaction with persons with visual and severe/profound intellectual disabilities (V-S/PID). In previous chapters, the Bioresponse system has been validated on feasibility, accuracy, and usability. However, the effects of the Bioresponse system on the quality of the interaction between professional caregivers and persons with V-S/PID has not yet been studied. Since validation through self-report is not possible with persons with V-S/PID, the quality of interaction is evaluated with indirect measures of the interaction's quality, as formulated by the research subquestion 2d "What is the effect of the monitoring system on the interaction between professional caregivers and persons with V-S/PID as measured by the caregiver's sensitive responsiveness, the client's joint attention behavior, the client's challenging behavior, and the dyad's affective mutuality?" This chapter focuses on evaluating the effects on the caregiver's sensitive responsiveness and the client's challenging behavior.

Chapter 11 Evaluating the effect of the Bioresponse system on Sensitive Responsiveness & Challenging Behavior

11.1 Introduction

Professional caregivers have a considerable influence on the quality of life for individuals with severe/profound intellectual disabilities (S/PID) since these individuals depend on their caregivers for daily care and social interaction (Wolff, Clary, Harper, Bodfish, & Symons, 2012). However, the subtle communicative behavior of clients with S/PID can be complex for caregivers to understand and interpret. These clients mostly communicate non-verbally and with limited symbolism (e.g., using eye gaze, vocalizations, facial expressions, and gestures to express themselves) (Griffiths & Smith, 2016). Prevalence of additional impairments, such as visual impairments, is common for persons with S/PID (Evenhuis, Theunissen, Denkers, Verschuure, & Kemme, 2001), and can complicate the understanding and interpretation of the client's communicative behavior further through the lack of eye contact and eye gaze, and reduced facial and emotional expressions (van den Broek et al., 2017).

These communicative impairments are known to be a cause for challenging behavior (CB; Poppes, Van der Putten, & Vlaskamp, 2010). Individuals with S/PID tend to show CB on a daily or weekly basis (Poppes et al., 2010). Janssen, Schuengel, and Stolk (2002) suggest that experiencing elevated levels of stress on a regular basis results in the client's biological response system constantly being activated. Consequently, even small stressful events can trigger the occurrence of CB. Sterkenburg, Schuengel, and Janssen (2008) have shown that caregivers can prevent high levels of stress, which is likely to result in less CB, by reacting sensitively to the client's communicative behavior. Increasing the caregiver's sensitive responsiveness could therefore lead to lower levels of stress and decreased occurrence of CB for the client.

The first step to improving sensitive responsiveness is to enhance the caregiver's understanding of the client's specific communicative behavior and the caregiver's ability to interpret this behavior accurately. Next, the caregiver's selection of appropriate responses that are adapted to the client's communicative abilities needs to be reinforced (Damen, Kef, Worm, Janssen, & Schuengel, 2011). Video feedback is an example of a method that is developed to improve sensitive responsiveness. In a video feedback intervention, an instructor supports participants by observing and discussing the interaction recorded on video together with the participant.

Damen and colleagues (2011) have used CONTACT, a video feedback program, with professional caregivers of children and adults with visual and intellectual disabilities and found an improved quality of interaction as a result of this intervention. Van den Broek and colleagues (2017) developed a video feedback intervention, Video Interaction for Positive Parenting for parents of children with Visual and visual-and-intellectual disabilities (VIPP-V). In a study on the effects of VIPP-V, no improvement in parent's sensitive responsiveness, but an improvement in parent's self-efficacy was observed (Platje, Sterkenburg, Overbeek, Kef, & Schuengel, 2018). In a study for parents with adopted children, more sensitive parenting behavior was found as a result of VIPP (Juffer, Struis, Werner, & Bakermans-Kranenburg, 2017).

Although effective (Van den Broek et al., 2017; Platje et al., 2018), a video feedback intervention is time-intensive and requires the involvement of qualified instructors. The use of physiological signals may offer an opportunity to enhance caregivers' sensitive responsiveness in their daily work environment with minimum investment in time and training. Stress and emotional arousal are known to influence the physiological balance of the autonomic nervous system (Mokhayeri, Akbarzadeh-T, & Toosizadeh, 2011) and can, therefore, be measured using physiological signals such as skin conductance (SC), heart rate (HR), heart rate variability (HRV), skin temperature (ST), and respiration (RSP). Through observing the client's physiological signals, caregivers may receive additional cues about the client's stress and emotional arousal levels, which support the caregiver's interpretation of the client's communicative behavior.

Based on these assumptions, Kobayashi, Nunokawa, and Ooe (2009) developed a system that measured the HR wave of persons with a severe motor and intellectual disability and provided caregivers with automatically detected information on alterations in HR (e.g., acceleration, deceleration, no response, or error). They demonstrated the feasibility of this kind of system by comparing observed behavioral reactions with HR measurements. Similarly, Lima et al. (2012) and Lima, Silva, Amaral, Magalhães, and de Sousa (2013) compared the ability to detect responses to stimuli in a child with profound intellectual and multiple disabilities using HR and motoric behavior observations. They noticed that the HR signal detected more responses to stimuli than the behavioral observations. Vos et al. (2012) and Vos, De Cock, Petry, Van Den Noortgate, & Maes (2013) studied the use of physiological signals as a supporting tool to behavioral observations to interpret the emotions of individuals with S/PID. They measured HR, HRV, SC, ST, and RSP during four positive and four negative stimuli and were able to discriminate between positive and negative stimuli for ST (Vos et al., 2012), HRV and RSP (Vos et al., 2013), but not for HR and SC.

Similarly, in the study described in chapter 3, SC was measured with children with Prader-Willi syndrome (aged 8 – 30 months) in both positive and negative situations naturally occurring in their home environment. Despite not being able to distinguish between positive and negative situations, the study's results include positive reactions from parents on the ability of the SC measurements to show their child's (emotional) responses to stimuli, which were not always observable in the child's behavior. This result has led to the development of the Bioresponse system, which is described in chapter 5. The Bioresponse system provides caregivers with feedback on the client's general arousal level using skin resistance (SR). Alterations in these general arousal levels can raise caregivers' awareness about changes in their client's behavior and invite them to study the client's communicative behavior more closely. We expect that through feedback on the client's general arousal levels caregivers gain a deeper knowledge of the client's specific communicative behavior and as a result improve the caregiver's sensitive responsiveness.

The aim of this study is to observe the efficacy of the Bioresponse system on the caregiver's sensitive responsiveness and the client's CB. The results on the effects of the Bioresponse system on the dyad's affective mutuality and the client's joint attention behaviors are reported in chapter 12. We expect that the use of the Bioresponse system leads to an enhanced level of caregivers' sensitive responsiveness, which will result in decreased frequencies and/or durations of the clients' CB.

11.2 Methods

11.2.1 Study design

The efficacy of the Bioresponse system on the caregiver's sensitive responsiveness and the client's challenging behavior is studied in a randomized multiple baseline study. In this study, consisting of a baseline phase (duration: 14 - 31 days), an intervention phase (duration: 12 weeks), and a follow-up phase (duration: 2 weeks), participants were observed using video recordings and skin resistance (SR) measurements. These observations were repeated seven times for each phase, allowing every participant to be his/her own control person (Kratochwill & Levin, 2010). A pause (duration: 3 weeks) between intervention and follow-up phases prevented effects resulting from the intervention to be measurable in the follow-up phase.

Following the method of Bulté and Onghena (2009), participants were randomly assigned to three groups with varying starting moments of the baseline phase (Table 11.1). The study design intended to include six participants equally divided over the groups. An independent researcher from the Vrije Universiteit Amsterdam determined the starting moment for each group through drawing lots, following the conditions that one group should start on day 1, the starting points should be at least four days apart, and the baseline length should vary between 14 and 31 days.

11.2.2 Participants

Developmental psychologists from Bartiméus and Royal Dutch Visio, two Dutch organizations providing support for persons with visual and/or intellectual disabilities, suggested 12 client-caregiver dyads for participation. The selected clients had to be older than 18 years, have a severe/profound intellectual disability as defined in their personal files, have a visual disability as defined in the World Health Organization standards (1980), be able to participate for the

Clients	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21
Client A		A	A	A	B	B	B	B	B	B	B	B	B	B	B	B				C	C
Client B			A	A	B	B	B	B	B	B	B	B	B	B	B	B				C	C
Client C	A	A	A	A	B	B	B	B	B	B	B	B	B	B	B	B				C	C
Client D			A	A	B	B	B	B	B	B	B	B	B	B	B	B				C	C

Note: A = Baseline phase; B = Intervention phase; C = Follow-up phase.

Table 11.1 Randomised Multiple Baseline Design with varying baseline lengths

Client	Age	Gender	Intellectual disability	Developmental age	Visual disability	Caregiver	Gender	CE[1]	CEC[2]
A	45	Male	Severe	25 - 36 months	Blind	A	Female	>5	>5
B	35	Female	Profound	8 - 10 months	Partial sight	B	Female	>5	>5
C	29	Female	Profound	2 - 4 months	Partial sight	C	Female	>5	>5
D	39	Female	Profound	11 - 13 months	Blind	D	Male	>5	1 - 2

Note: 1 CE = Caregiver's Experience of working with the target group in years; 2 CEC = Caregiver's Experience of working with the participating client in years.

Table 11.2 Participants' demographic information

duration of the study, and be able to remain seated during the observations. Eight client-caregiver dyads were randomly selected and invited for participation in this study. Written consent for participation was obtained from the caregivers and the client's legal representatives. This study received ethical approval from the Medical Ethical Committee from the Vrije Universiteit medical center, Amsterdam, the Netherlands (reference number: NL53963.029.15; see also chapters 9 and 10).

Four client-caregiver dyads completed the study; their characteristics can be found in Table 11.2. The dyad's demographic information was provided to the researchers by the participating caregiver through a questionnaire and completed by the developmental psychologists with information from the client's personal files, such as the level of intellectual disability. The other four dyads were unable to finish participation due to the tasks not matching the caregivers' expectations (see also Chapter 9, page 109), the tasks being too strenuous for the client (see also Chapter 9, page 109), or due to the client showing resistance towards the sensor used in this study. The remaining dyads on the list could not participate due to time constraints or were excluded because another dyad from the same residence already participated.

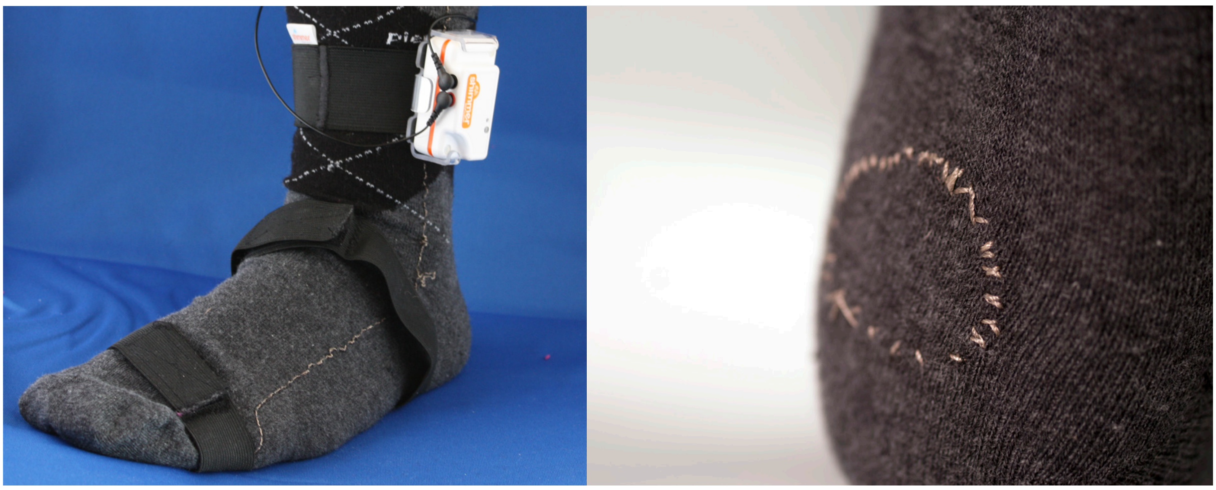


Figure 11.1 Sensor sock.
Panel 11.1A: Sensor sock with a Shimmer 2R Biophysical module.
Panel 11.1B: Integrated fabric electrode (photo: M. Croes).

11.2.3. Intervention

The Bioresponse system aims to enhance the caregiver's sensitive responsiveness to the client's communicative behavior by providing them with feedback on the client's general arousal level and general response to environmental stimuli (e.g., music in the background or the caregiver's voice). The system uses a sock with embedded fabric electrodes, connected to a Shimmer 2R BioPhysical sensor (Shimmer, Dublin, Ireland), to measure SR over the client's foot sole (Figure 11.1). The Shimmer sensor sends the measured SR data wirelessly to a tailor-made Android application developed by M. Croes, L. Vork, and P. Peters (Eindhoven University of Technology, Eindhoven, the Netherlands).

In the application, the SR signal is displayed in the shape of a flower. The size of the flower increases based on an increasing SR signal when the general arousal level decreases. When the general arousal level increases, the skin resistance decreases and the size of the flower will decrease (Figure 11.2A). Small peaks in the SR signal represent the client's reactions to stimuli in the environment. The number of small peaks is reflected in the opacity of additional (orange) flower petals. Detecting more peaks in the SR signal results in the additional flower petals becoming more visible due to a decreasing opacity of these petals (Figure 11.2B).

Caregivers can use the Flower app as well to record their behavioral observations of the client with the use of six colored buttons displayed next to the flower. Each colored button represents

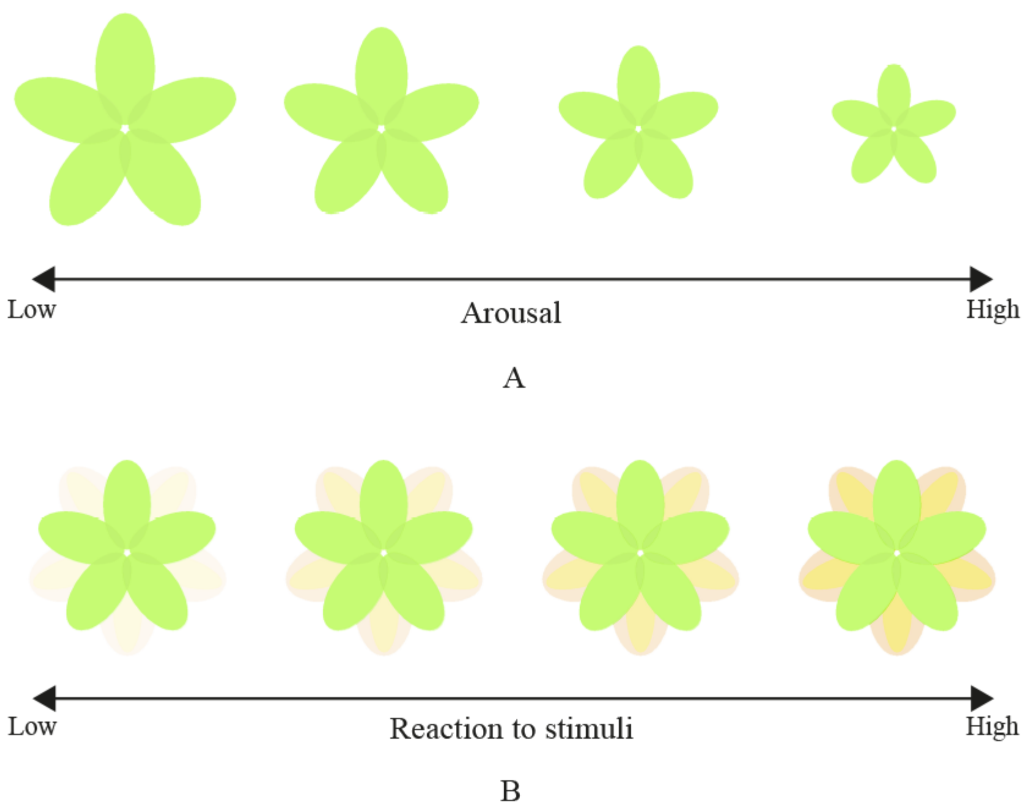


Figure 11.2 The visualization of the flower in the Flower app.
Panel 11.2A: The flower's size decreases when the arousal level increases, and vice versa.
Panel 11.2B: The additional flower petals become more visible if the reaction to stimuli becomes stronger.

an arousal state — with purple standing for “low alertness”; blue for “understimulated”; green for “relaxed”; yellow for “a little tense”; orange for “tense”; and red for “stressed” (these colors and their meaning are taken from the “signaling list” (in Dutch: signaleringsplan), a tool to support the interpretation of the client’s behavior).

For the baseline and follow-up phases, the Bioresponse system was only used during the observations, in which the application recorded the SR signal, but displayed a blank screen. The feedback (the flower) was only presented to the caregivers in the intervention phase. In this phase, the caregivers used the Bioresponse system both during the observations and during daily care moments of the caregiver’s selection. Caregivers were encouraged to use the system during each shift they worked with the participating client for at least ninety minutes. Before the intervention phase started, caregivers were given a short, individual training on the use of the Bioresponse system and the interpretation of the flower visualization.

11.2.4 Procedures

Each observation consisted of three activities: a play moment, a daily care moment, and the Three Boxes procedure (NICHD Early Child Care Research Network, 1999, 2003). The first activity was a structured play moment, inspired by the Early Social Communication Scale tasks (Mundy et al., 2003), in which the caregiver and client interacted with three toys (each for 2 -3 minutes) and sang songs together (for approximately 2 - 3 minutes). The selection of toys provided by the researchers consisted of tangible and/or audible interactions that could be operated individually or in collaboration. When adequate, the selection was extended with the client’s toys. The second activity (10 minutes) was a daily care moment of the caregiver’s selection. Three caregivers chose to have lunch or a snack, and one caregiver selected a moment when the client was sitting on her lap.

In the Three Boxes procedure, the caregiver was instructed to guide the client through 15 minutes of play, using the toys presented by the researcher (NICHD Early Child Care Research Network, 1999, 2003). Since the Three Boxes task is originally intended for parents and children, the materials for this task had to be adapted to the abilities of the participating clients. The toys were presented in bags, labeled 1 to 3, with the first bag containing a tactile reading book, the second bag containing a pop-up puppet, and the third bag containing a cuddly toy. The caregiver was instructed to divide the time over the three bags as he/she deemed fit, as long as they started with bag 1 and finished with bag 3. Due to one of the clients having an aversion to touching objects, the tactile reading book was replaced with the client’s storybook. Three clients were not interested in interacting with the pop-up puppet; therefore, a musical instrument replaced the pop-up puppet.

11.2.5 Instruments

Sensitive responsiveness

The caregiver’s sensitive responsiveness is measured with the parental scale of the 24-month version of the National Institute of Child Health and Human Development (NICHD) scales (Brady-Smith, O’Brien, Berlin, Ware, & Brooks-Gunn, 1999). The parental scale, consisting of the subscales “parental sensitivity”, “parental intrusiveness”, “parental stimulation of cognitive development”, “parental positive regard”, “parental negative regard,” and “parental detachment”, was used to evaluate the Three Boxes procedure by rating the subscales on a 7-point Likert scale. The Sensitive Responsiveness score was determined by the summed scores of the subscales “parental sensitivity” and “parental positive regard”, and the inverted scale scores of “parental intrusiveness”, “parental negative regard,” and “parental detachment”.

Four master’s students Clinical Psychology at the Vrije Universiteit Amsterdam were trained in the NICHD-scales by Prof. C. Schuengel, an NICHD registered trainer, Dr. M. Oosterman, and Prof. P. Sterkenburg at the Vrije Universiteit Amsterdam, Amsterdam, the Netherlands. The students scored the video recordings of the Three Boxes task in random order and blind to the phase of the study. As each video was coded twice, consensus scores (when the observers’ scores differed two points or more) or average scores (when the observers’ scores differed less than two points) were used for analysis purposes. The Intra Class Correlation (ICC) for the parental scale was .82. A higher ICC of .99 was observed in a comparable study from Sterkenburg and Schuengel (2010).

Challenging behavior

The client’s challenging behavior was measured with a self-developed scoring manual consisting of three scales: aggressive behavior (AB), self-injuring behavior (SIB), and stereotyped behavior (SB) (see appendix D on page 208 for the coding manual). This manual was based on the “Behavior Problems Inventory” (Rojahn, Matson, Lott, Esbensen, & Smalls, 2001). The AB scale has ten subscales: “hitting”, “kicking”, “pushing”, “grabbing/pulling”, “scratching”, “pinching”, “biting”, “spitting”, “damaging objects”, and “verbally aggressive”. The SIB scale consisted of the subscales “hitting self”, “kicking self”, “pulling hair”, “scratching self”, “pinching self”, “biting self”, “eye-poking”, and “vomiting”. The SB scale has seven subscales: “rocking”, “head-rolling”, “repetitive pointing”, “repetitive waving”, “teeth grinding”, “yelling”, and “screaming”. The occurrence and duration of behaviors listed under each scale were scored using Noldus The Observer version 10.5 software (Noldus Information Technology, Wageningen, the Netherlands). Two independent observers, master’s students in Clinical Psychology at the Vrije Universiteit Amsterdam, independently scored all the video recordings of the three tasks. The order of the videos was randomized and indications of the phase in which the video was recorded were removed. Average frequencies and durations of the coded behaviors were used in the analyses. The challenging behavior was scored for each activity separately. Next, the average frequencies and durations were summed for a combined score per observation. The percentages of agreement on the frequency of AB, SIB, and SB behaviors were 64.3%, 71.8%, and 43.6% respectively and 98.4% (AB), 96.7% (SIB), and 87.9% (SB) for the duration of these behaviors. Cohen’s kappa was for the frequency .61 (AB), .69 (SIB), and .37 (SB) and .98, .96, and .87 respectively for the duration.

11.2.6 Analysis

The analysis of this study is based on observational data; the physiological data was only used as feedback for the caregivers during the intervention phase. The first step in the analysis was to inspect the trend of the sensitive responsiveness scores and the trend of the frequency and the duration of challenging behavior. The visual inspection used regression lines and regression coefficients (RC) to support the interpretation: an increasing regression line and positive RC were labeled as a positive trend and a decreasing regression line and negative RC as a negative trend. The trend was further classified as slight ($-0.5 > RC < 0.5$), moderate ($0.5 < RC < 5$ or $-5 < RC < -0.5$), or steep ($RC > 5$ or $RC < -5$).

The second step in the analysis was a repeated measure Friedman's ANOVA, which tested for each dyad separately whether a significant difference ($\alpha = 0.05$) in sensitive responsiveness scores and the frequency and duration of CB scores is present between the baseline, intervention, and follow-up phases. As each phase existed of only seven observations, a non-parametric method – the Friedman's ANOVA - was used. A meta-analysis, as described by de Weerth and van Geert (2002), combined the results of the four participating dyads by summing the natural logarithms of each p-value and multiplying the sum by -2. P-values smaller than .005 were substituted for a value of .01, and for changes in unexpected directions, a value of .5 was used instead of the actual value. The combined results followed a chi-squared distribution (with degrees of freedom = 2 * number of cases).

11.3 Results

11.3.1 Sensitive responsiveness

Due to faulty recording equipment, one video from Dyad D was not available for analysis. The sensitive responsiveness scores were not significantly different in the baseline, intervention, and follow-up phases; neither for the individual caregivers nor for their combined scores (Table 11.3). For Caregivers B and C, the mean sensitive responsiveness scores indicated a higher score for the intervention phase compared to the baseline and follow-up phases. Although the mean sensitive responsiveness scores for the follow-up phase were lower than the intervention phase, these scores were higher compared to the baseline phase. For Caregivers A and D, the mean scores decreased from the baseline to the intervention phase and further decreased to the follow-up phase (Table 11.4).

Visual inspection of the sensitive responsiveness scores revealed a moderate positive trend for Caregivers A, C, and D during the intervention phase with a regression coefficient (RC) of 0.55, 0.63, and 1.15 respectively (Figure 11.3A, C, and D). Caregivers A and C showed a lower, however still a slight to moderate positive trend in the follow-up phase (A: 0.08 and C: 0.52). Caregiver D has a moderate negative trend in the follow-up phase (RC: -0.96). Caregiver B showed a slightly negative trend in the intervention phase (RC: -0.16); however a slight to moderate positive trend in the baseline and follow-up phases (RC: 0.02 and 0.61 respectively) (Figure 11.3B).

11.3.2 Challenging Behavior

Six videos from client A and three from client D were excluded for analysis due to technical problems with the video files and for fourteen videos, scores were not available after the coding phase. The analysis was performed on the summed and averaged scores of the 232

Scale		Caregiver A		Caregiver B		Caregiver C		Caregiver D		Combined	
Sensitive Responsiveness	χ^2	2.30		0.52		5.41		0.33		8.56	
	df	2		2		2		2		8	
	p	0.32		0.77		0.07		0.85		> 0.25	
Scale		**Client A**		**Client B**		**Client C**		**Client D**		**Combined**	
		Frequency	Duration	Frequency	Duration	Frequency	Duration	Frequency	Duration	Frequency	Duration
Aggressive Behaviours (AB)	χ^2	3.50	3.85	-	-	3.88	3.88	3.43	3.43	10.80	11.15
	df	2	2	-	-	2	2	2	2	8	8
	p	0.17	0.15	-	-	0.18	0.14	0.18	0.18	> 0.10	> 0.10
Self-injuring Behaviors (SIB)	χ^2	0.00	0.00	2.00	2.00	1.24	0.67	0.00	0.00	3.24	2.67
	df	2	2	2	2	2	2	2	2	8	8
	p	1.00	1.00	0.37	0.37	0.54	0.72	1.00	1.00	> 0.25	> 0.25
Stereotyped Behaviors (SB)	χ^2	1.14	0.86	0.29	4.57	0.29	5.43	1.52	0.96	3.23	11.82
	df	2	2	2	2	2	2	2	2	8	8
	p	0.57	0.65	0.87	0.10	0.87	0.07	0.47	0.62	> 0.25	> 0.10

Table 11.3 Friedman's ANOVA test and meta-analysis (four clients combined) results of comparing the baseline, intervention and follow-up phase

		Baseline		Intervention		Follow-up	
Scale	Caregiver	Mean (SD)		Mean (SD)		Mean (SD)	
Sensitive Responsiveness	Caregiver A	5.17 (0.47)		4.68 (0.67)		4.32 (1.28)	
	Caregiver B	2.89 (1.19)		3.61 (1.32)		3.25 (1.70)	
	Caregiver C	2.00 (0.71)		3.04 (1.08)		2.43 (1.46)	
	Caregiver D	2.78 (1.17)		2.58 (1.34)		1.75 (0.60)	
		Frequency	**Duration**	**Frequency**	**Duration**	**Frequency**	**Duration**
Scale	Client	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Aggresive Behaviors (AB)	Client A	0.00 (0.00)	0.00 (0.00)	0.43 (0.73)	1.32 (2.34)	0.29 (0.57)	0.42 (1.02)
	Client B	0.00 (0.00)	0.00 (0.00)	0.00 (0.00)	0.00 (0.00)	0.00 (0.00)	0.00 (0.00)
	Client C	0.43 (0.54)	0.77 (1.56)	0.00 (0.00)	0.00 (0.00)	0.29 (0.49)	1.04 (2.02)
	Client D	14.57 (7.24)	40.70 (23.00)	29.71 (21.62)	121.08 (123.55)	31.00 (15.88)	89.27 (51.46)
Self-injuring Behaviors (SIB)	Client A	0.36 (0.95)	3.80 (10.05)	0.36 (0.95)	3.80 (10.05)	0.07 (0.19)	0.31 (0.83)
	Client B	0.07 (0.19)	0.30 (0.80)	0.07 (0.19)	0.30 (0.80)	0.00 (0.00)	0.00 (0.00)
	Client C	3.57 (7.55)	30.86 (70.17)	8.64 (10.90)	125.77 (166.23)	9.34 (9.71)	79.13 (86.41)
	Client D	14.75 (10.23)	34.85 (28.97)	12.07 (9.41)	31.42 (30.81)	9.79 (6.51)	22.91 (15.46)
Stereotyped Behaviors (SB)	Client A	22.57 (13.14)	781.18 (519.37)	25.36 (14.19)	702.98 (437.68)	19.93 (6.79)	635.07 (315.50)
	Client B	106.50 (41.99)	1376.13 (548.85)	108.93 (34.13)	1767.63 (431.38)	113.57 (20.05)	1805.19 (273.77)
	Client C	54.00 (44.71)	286.57 (260.48)	41.14 (11.82)	232.38 (75.70)	58.00 (23.32)	459.63 (132.45)
	Client D	7.50 (8.27)	18.78 (25.94)	24.79 (39.92)	57.86 (93.56)	20.14 (25.31)	106.21 (122.22)

Table 11.4 Average frequency and duration of Sensitive Responsiveness and Challenging Behavior per phase

11

remaining videos. The challenging behavior scores were not significantly different in the baseline, intervention, and follow-up phases. The meta-analysis of the combined results also did not significantly differ (Table 11.3). The frequency and duration of AB for clients A, B, and C, and of SIB for clients A and B were so low that they are considered as not occurring (a maximum occurrence of 2 times with a maximum total duration of 26.6 seconds over a period of approximately 35 minutes). The mean frequency of client D's SIB and client C's SB was lower for the intervention phase compared to the baseline phase. Client D's mean frequency of SIB continued to decrease in the follow-up phase; however, client C's mean frequency of SB increased during the follow-up phase. The mean frequency of SIB for client C and of SB for clients A, B, and D increased during the intervention phase compared to the baseline phase. For client A and D, the mean frequency of SB was lower during the follow-up phase than for the intervention phase and for client A the mean frequency during the follow-up phase was even lower than for the baseline phase (Table 11.4). Due to the substantial interrater agreement on the frequency of AB and SIB and the moderate interrater agreement on the frequency of SB behaviors, these results need to be interpreted with caution. The mean duration of client D's SIB and the mean duration of clients A and C's SB were lower for the intervention phase compared to the baseline phase. For client D's SIB and client A's SB, the mean duration continued to decrease for the follow-up phase. The mean duration for client B's SB, client C's SIB, and client D's AB and SB increased from the baseline phase to the intervention phase. For client D's AB and client C's SIB, the mean duration for the follow-up phase was lower than during the intervention phase, however not lower than for the baseline phase (Table 11.4).

The visual inspection of the challenging behavior scores showed a slight negative trend in frequency for client A's SB (RC: -0.16) and client D's SIB (RC: -0.41) (Figure 11.4). This trend was confirmed in the duration scores with a steep decline in SB for client A (RC: -12.01) and a moderate decrease of SIB for client D (duration RC: -1.15). A slightly increasing trend in frequency was observed for client B's SB (RC: 0.43) and a moderate incline for client C's SIB and SB with respectively RC: 0.58 and RC: 0.97, and client D's AB (RC: 1.13) and SB (RC: 1.12). The duration also showed an increase for these scales with a moderate incline for client D's AB (RC: 3.08) and steep increasing trends for the SIB of client C (RC: 6.06) and the SB of clients B, C, and D (with RC: 32.37, RC: 12.47, and RC: 6.90 respectively).

11.4 Discussion

The results from this randomized multiple baseline study suggested that the Bioresponse system may have potential for positively influencing the caregiver's sensitive responsiveness. Three out of four caregivers had a positive trend in sensitive responsiveness during the intervention phase and two out of four caregivers had a higher mean sensitive responsiveness score for the intervention phase compared to the baseline and follow-up phases. For these caregivers, the mean score in the follow-up phase was also higher compared to the baseline phase. Two clients showed a decreasing trend on one subscale of CB behavior and three clients had a lower mean duration of one subscale of CB behavior.

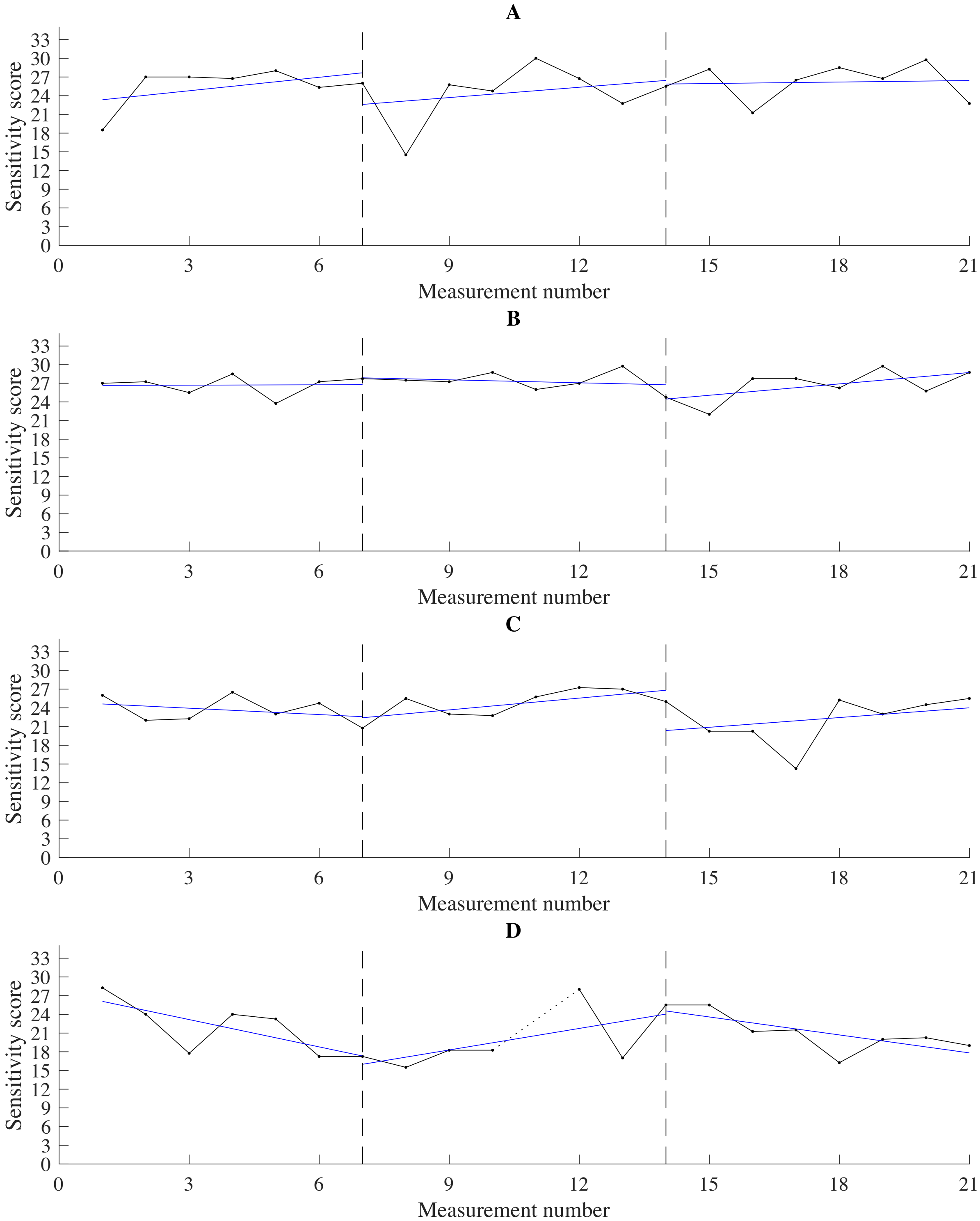


Figure 11.3 Regression lines for Sensitive Responsiveness scores

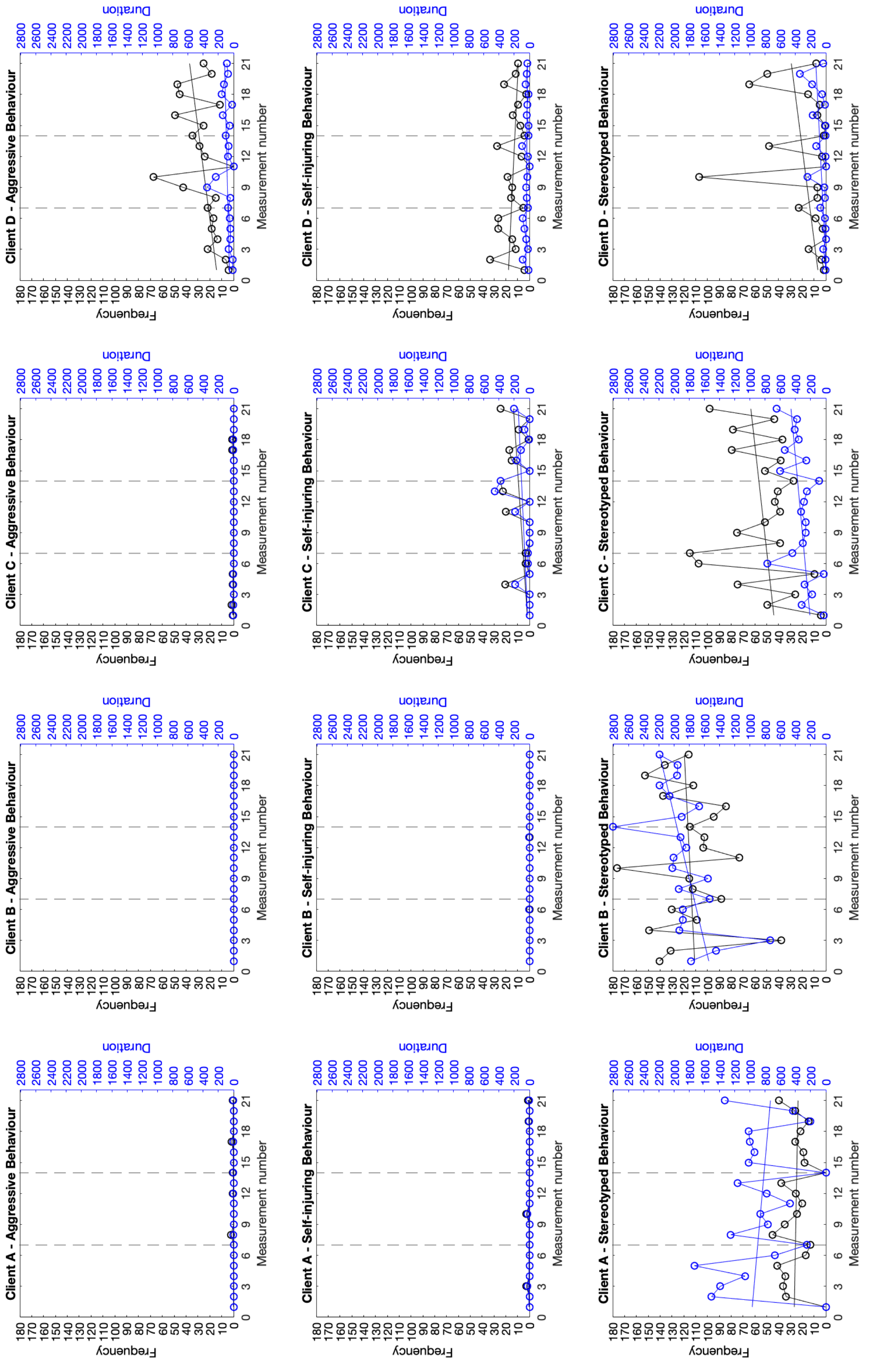


Figure 11.4 Frequency (black) and duration (blue) of Aggressive Behaviors (top), Self-injuring Behaviors (middle), and Stereotyped Behaviors (bottom).

However, after having finished the data collection, it became apparent that the intervention had not worked as intended for two reasons: 1) the flower in the app did reflect skin resistance (SR) and not skin conductance (SC), and 2) the flower in the app lacked in sensitivity. As SC is the opposite of SR (as defined by the formula: SR = 1/SC), the flower's behavior was reversed. Caregivers were instructed to expect increasing arousal levels when observing an increasing flower size. While in actuality, an increasing flower size meant a decreasing arousal level. The other way around when caregivers observed a decreasing flower size, they were instructed to interpret this as decreasing arousal levels, while it should be interpreted as increasing arousal levels. This reversed behavior of the flower could potentially lead to the misinterpretation of the client's communicative behavior.

However, since the size of the flower was logged into a data file 51 times per second for the duration of each measurement, the actual behavior of the flower could be checked. It was discovered that no misinterpretation of the flower's size occurred since the flower did not change in size at all, even though it should have changed given the sensor's measurements. The size of the flower was checked by calculating the intended flower's size, using the same formula as was used in the code of the app, from the recorded SR data. The study existed of 84 intervention measurements (4 dyads * 7 measurements per dyad * 3 activities per measurement). For 3 of those measurements, no SR data was recorded due to technical failures, and for 14 measurements the SR data belonging to the measurement could not reliably be separated from the entire SR data recording. For the remaining 67 measurements, the recorded SR data is compared to the recorded flower size. In 36 measurements, the flower app did correctly not alter in size. In 31 measurements, the flower should have displayed fluctuations in the flower's size. Due to the measurement of SR instead of SC and the app's failure to adapt the flower's size in real-time, no conclusions can be drawn with regards to the effect of the Bioresponse system on the caregiver's sensitive responsiveness and the client's challenging behavior.

Furthermore, the size of the flower is not the only form of feedback the flower provides. The flower also displays additional petals when peaks — which reflect reactions to stimuli in the environment — are detected in the SR signal. Although the size of the flower remained constant, the feedback from the additional petals did function and provided the caregivers with a form of feedback. Again, the feedback was based on SR instead of SC and, although the peaks detected in the SR signal correspond to dips in the SC signal, the feedback did capture the same variation in the signal and thereby the changes in reactions to the stimuli in the environment.

11.5 Lessons learned

This study has not yielded results on the effects of the Bioresponse system on the quality of interaction. However, it has provided insights in developing and studying monitoring systems. Even though the flower's size did not change, caregivers were observed to reflect on their behavior towards the client. Noticing changes in the additional petals triggered caregivers to watch the client's communicative signals more closely and to monitor both the client's behavior and the Flower app for effects on changing their own behavior. Having a tool that supports the detection and interpretation of the client's communicative signals might in itself stimulate caregivers to reflect on their actions.

For future studies, it would be advisable to include a check protocol in the study's protocol. This check protocol should test whether the feedback is working and functioning as intended. An example of check protocol would be a short test situation of a relaxation and a stressful moment (e.g., a breathing exercise and an arithmetic exercise). The study's protocol should also include a more strict filming protocol. In the current study, the protocol subscribed to place the tablet in the camera view and start the video recording before starting the program in the Flower app. However, synchronizing the video recording with the sensor measurements proved challenging. The moment of pressing the program's start button was not always reliably visible; for example, due to the hand used to start the program blocking the view of the tablet screen. Furthermore, the app showed a delay of 1 to 5 seconds after pressing the start button to actually start the recording of the SR data. Next to pressing the start button, moments of caregivers using the buttons to record their behavioral observation were recorded, which could reliably be matched to the registration of the button press in the app. A new study protocol should include a protocol for reliably synchronizing the video recordings to the sensor measurements. An example of this protocol could be requiring to hold the tablet PC in front of the video camera and visibly pressing one of the colored buttons at the start and the end of the measurement. This provides two time points that can be reliably matched from the video recording to the sensor measurement.

This study has used repeated measurements of the measures for sensitive responsiveness and challenging behavior, which typically are included as a singular measurement in study designs. The results for these measures have proven to fluctuate over time. It might be interesting for future studies to examine which factors cause the fluctuations in these results, e.g., time of day, location within the group home, or whether other clients or caregivers are present. These measures are time-intensive and, therefore, often applied as singular measurements. This study has indicated that repeated measurements are feasible without overloading clients and that caregivers are willing to invest the time and effort in repeat measurement studies.

11.6 Conclusion

Although the intervention did not work as intended and no conclusions from the data can be drawn, the Bioresponse system seems to show a potentially positive effect on the quality of interaction between professional caregivers and adults with visual and severe or profound intellectual disabilities. The flower in the Flower app did not alter in size, but did provide feedback through the additional flower petals. Therefore, the use of the Bioresponse system may have triggered caregivers to look more closely at the communicative signals of the client. Perhaps, as a result, three out of four caregivers had a positive trend in sensitive responsiveness during the intervention phase and two out of four caregivers had a higher mean sensitive responsiveness score for the intervention phase compared to the baseline and follow-up phases. Furthermore, two clients showed a decreasing trend on one subscale of CB behavior and three clients had a lower mean duration of one subscale of CB behavior. A repeated study, preferably with a larger sample, is required for conclusions on the effect of a Bioresponse system on the caregiver's sensitive responsiveness and the client's challenging behavior.

Preface

The previous chapter has answered the first part of the research subquestion 2d “What is the effect of the monitoring system on the interaction between professional caregivers and persons with V-S/PID as measured by the caregiver’s sensitive responsiveness, the client’s joint attention behavior, the client’s challenging behavior, and the dyad’s affective mutuality?” by evaluating the effects of the Bioresponse system on the caregiver’s sensitive responsiveness and the client’s challenging behavior. This chapter will complete the answer to research subquestion 2d by evaluating the system’s effects on the client’s joint attention behaviors and the dyad’s affective mutuality.

This chapter is based on: Frederiks, K., Sterkenburg, P., Barakova, E. & Feijs, L. (2019). The effects of a bioresponse system on the joint attention behaviour of adults with visual and severe or profound intellectual disabilities and their affective mutuality with their caregivers. *Journal of Applied Research in Intellectual Disability*, 1–11

Chapter 12 Evaluating the effect of the Bioresponse system on Joint Attention and Affective Mutuality

12.1 Introduction

The quality of interaction considerably contributes to the quality of life for individuals with severe or profound intellectual disabilities (S/PID; Forster & Iacono, 2014). High-quality social interactions add to the happiness, social connectedness, independence, and alertness of these individuals (Hostyn & Maes, 2009). However, the success of their interaction is often hindered due to their communication being mostly non-verbal with an idiosyncratic nature and limited symbolism. This subtle communicative behavior can be challenging for others to detect and interpret (Griffiths & Smith, 2016).

Severe or profound intellectual disabilities are conjoined with a high prevalence of visual impairments (Evenhuis, Theunissen, Denkers, Verschuure, & Kemme, 2001). A lack of eye contact and gaze following hinders both interaction partners in noticing whether they hold each other's attention. Attuning between interaction partners is complicated, when visual impairments occur, due to less distinct emotional expressions and absence of reciprocal emotional responses (van den Broek et al., 2017). Although subtle communicative behavior and visual impairments may inhibit the expression of emotions, the autonomic nervous system (ANS) is activated as a result of (emotional) arousal. This activation can be captured through monitoring biological signals, like heart rate (HR), skin conductance (SC), skin temperature (ST), and respiration (RSP; Mokhayeri, Akbarzadeh-T, & Toosizadeh, 2011).

Kobayashi, Nunokawa, and Ooe (2009) measured this ANS activation using HR to support the interaction between caregivers and individuals with a severe motor and intellectual disability. They presented HR responses (e.g., acceleration, deceleration, no response, or error) to create insight into the individual's behavioral response. Lima, Silva, Amaral, Magalhães, and de Sousa (2013) used HR to observe the responsiveness to stimuli of a child with profound intellectual and multiple disabilities. They were able to detect more responses to stimuli in the HR signal than they could observe in the child's motoric behavior. Vos and colleagues measured emotional arousal with HR, HRV, SC, ST, and RSP, and validated that observations of emotional behaviors from adults with S/PID are reflected in their HR, ST, and RSP (Vos et al., 2012; Vos, De Cock, Petry, Van Den Noortgate, & Maes, 2013).

Research involving these biological signals is typically conducted in laboratory environments; however, measuring these signals in the field holds the opportunity to understand social processes in real life (chapter 7). Although all studies described above have been conducted in the participants' homes, the nature of their study required approximating laboratory conditions by removing as many non-targeted stimuli as possible. Since the acceptance of new technology depends on its adaption to the user's needs (Light & McNaughton, 2013), we argue that the technology needs to apply to daily care and socialization situations, in which a stimuli-free environment is not feasible. To address this need, we developed a Bioresponse system, which measures emotional arousal through skin resistance (SR) and aims to improve joint attention behaviors in adults with a visual and severe or profound intellectual disability and the affective mutuality with their caregivers in daily practice. This system does not measure an (emotional) response to a specific stimulus but monitors the client's general (emotional) arousal. The system invites caregivers to observe the client's behavior more carefully by displaying changes in the general arousal level, resulting in a better understanding of this behavior. In a previous study, an early version of the monitoring system — the Sense system — was used with parents and their child with Prader–Willi syndrome (aged 8–30 months) to validate if the system can distinguish between positive and negative emotions when used in the home environment (Chapter 3). Since this distinction could not be made, the current version of the system was designed to monitor the client's general (emotional) arousal level, instead of emotions to specific stimuli or distinguishing between positive and negative emotions.

In the current study, the effect of the Bioresponse system on the quality of interaction is determined through measures of joint attention and affective mutuality. The effect of the system on the caregiver's sensitive responsiveness and the client's challenging behavior is reported in Chapter 11. Intellectual and multiple disabilities exclude the use of self-assessment measures to validate the effects on the dyad's interaction, which is why we chose to evaluate the quality of interaction using indirect measures of joint attention and affective mutuality. We hypothesized that the use of the Bioresponse system would result in increased frequency and/or duration of joint attention behaviors and elevated affective mutuality scores.

12.2 Methods

12.2.1 Study design

A randomized multiple baseline design was used to study the effects of a Bioresponse system on the client's joint attention behaviors and the dyad's affective mutuality (Table 12.1). This study consisted of three phases: (a) a baseline phase (duration: 14–31 days), (b) an intervention phase (duration: 12 weeks), and (c) a follow-up phase (duration: 2 weeks). The intervention phase was preceded by a short training session on the use of the Bioresponse system and followed by a 3-week break to prevent that the follow-up measurements were influenced by the effects of

Clients	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**	**15**	**16**	**17**	**18**	**19**	**20**	**21**
Client A		A	A	A	B	B	B	B	B	B	B	B	B	B	B	B				C	C
Client B			A	A	B	B	B	B	B	B	B	B	B	B	B	B				C	C
Client C	A	A	A	A	B	B	B	B	B	B	B	B	B	B	B	B				C	C
Client D			A	A	B	B	B	B	B	B	B	B	B	B	B	B				C	C

Note: A = Baseline phase; B = Intervention phase; C = Follow-up phase.

Table 12.1 Randomised Multiple Baseline Design with varying baseline lengths the intervention phase. To ensure that every participant could function as his/her own control person, video recordings and physiological signal measurements were recorded seven times in each phase, following the method of Kratochwill and Levin (2010). For a detailed explanation of determining the varying baseline lengths, please see Chapter 11, page 131.

12.2.2 Participants

Four client–caregiver dyads from two Dutch organizations that provide support and care for persons with visual and/or intellectual disabilities, Bartiméus (n = 2) and Royal Dutch Visio (n = 2), completed their participation in this study. These dyads were randomly selected from a list of 12 client–caregiver dyads. Developmental psychologists of both organizations selected these twelve dyads for participation based on the client meeting the following inclusion criteria:

- Clients are 18 years or older.
- Clients have a severe or profound intellectual disability, as defined in their personal files.
- Clients have a visual disability as defined in the World Health Organization standards (World Health Organization, 1980).
- Clients are able to participate during the complete period required for this study.
- Clients are able to remain seated for the duration of the video recording and physiological signal measurement.

The characteristics of the participating dyads are presented in Table 12.2. The caregivers and the client's legal representatives provided written consent for participation. The Medical Ethical Committee of the Vrije Universiteit Medical Center, Amsterdam, the Netherlands, approved this study (reference number: NL53963.029.15; see also Chapters 9, 10, and 11). The developmental psychologists employed at the two participating organizations provided the researchers with demographic information including the level of intellectual disability found in the client's personal files.

Although eight client–caregiver dyads started participation, only four dyads completed the study. One reason for ending the participation in this study was that the tasks for the video recordings were not conforming to the caregiver's expectations, as she felt the tasks did not live up to her promise to her client of having a fun time together during this study (see also Chapter 9, page 109). For one client, the participation ended due to a mismatch of the tasks with the

Client	Age	Gender	Intellectual disability	Developmental age	Visual disability	Caregiver	Gender	CE[1]	CEC[2]
A	45	Male	Severe	25 - 36 months	Blind	A	Female	>5	>5
B	35	Female	Profound	8 - 10 months	Partial sight	B	Female	>5	>5
C	29	Female	Profound	2 - 4 months	Partial sight	C	Female	>5	>5
D	39	Female	Profound	11 - 13 months	Blind	D	Male	>5	1 - 2

Note: 1 CE = Caregiver's Experience of working with the target group in years; 2 CEC = Caregiver's Experience of working with the participating client in years.

Table 12.2 Participants' demographic information

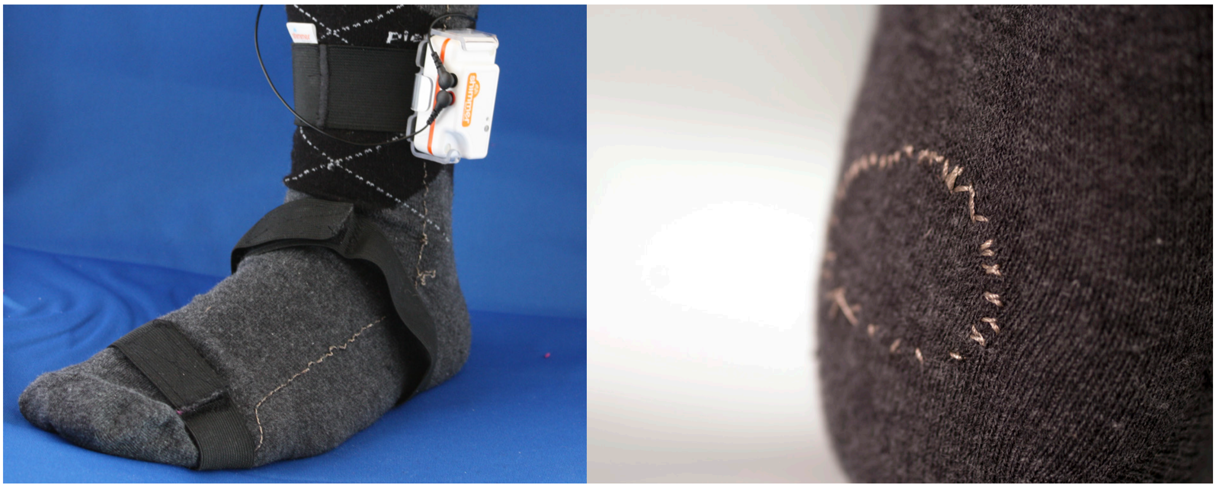


Figure 12.1 Sensor sock.
Panel 12.1A: Sensor sock with a Shimmer 2R Biophysical module.
Panel 12.1B: Integrated fabric electrode (photo: M. Croes).

client's attention span and interests (see also Chapter 9, page 109). The participation of two other clients was ended after they showed resistance to the sensor used in this study. The four remaining dyads on the list were not able to participate due to time limitations or were excluded because another dyad from the same group home was already participating in the study.

12.2.3 Intervention

The Bioresponse system is a tool to provide caregivers with additional cues to the client's communicative behavior and to enhance the caregiver's understanding of this behavior. This enhanced understanding allows the caregiver to better match his/her responses to the client's communicative signals. As a result, the affective mutuality between client and caregiver could increase, which may stimulate the client's use of joint attention behavior.

The system monitors skin resistance (SR) through a Shimmer 2R BioPhysical sensor (Shimmer, Dublin, Ireland) attached to a sock with integrated fabric electrodes (Figure 12.1). A tailor-made Android application developed by M. Croes, L. Vork, and P. Peters (Eindhoven University of Technology, Eindhoven, the Netherlands) receives the SR signal via Bluetooth. This application, running on a tablet PC, visualizes this signal in the shape of a flower. Increasing general arousal levels result in a decrease in the SR signal, and vice versa. These alterations in the SR signal are displayed in the flower through corresponding changes in the flower's size (Figure 12.2A). The client's responses to stimuli in the environment, such as hearing one's name or music in the background, are shown in the SR signal as small peaks. An increasing number of peaks detected in the signal is visualized within the application through the appearance of additional (orange) flower petals (Figure 12.2B).

The Bioresponse system was used in all observations made in this study; however, the application only provided visual feedback (the flower) during the intervention phase. During the baseline and follow-up phases, the application showed a blank screen, although the SR signal was still recorded in the background. In contrast to the baseline and follow-up phases, in the intervention

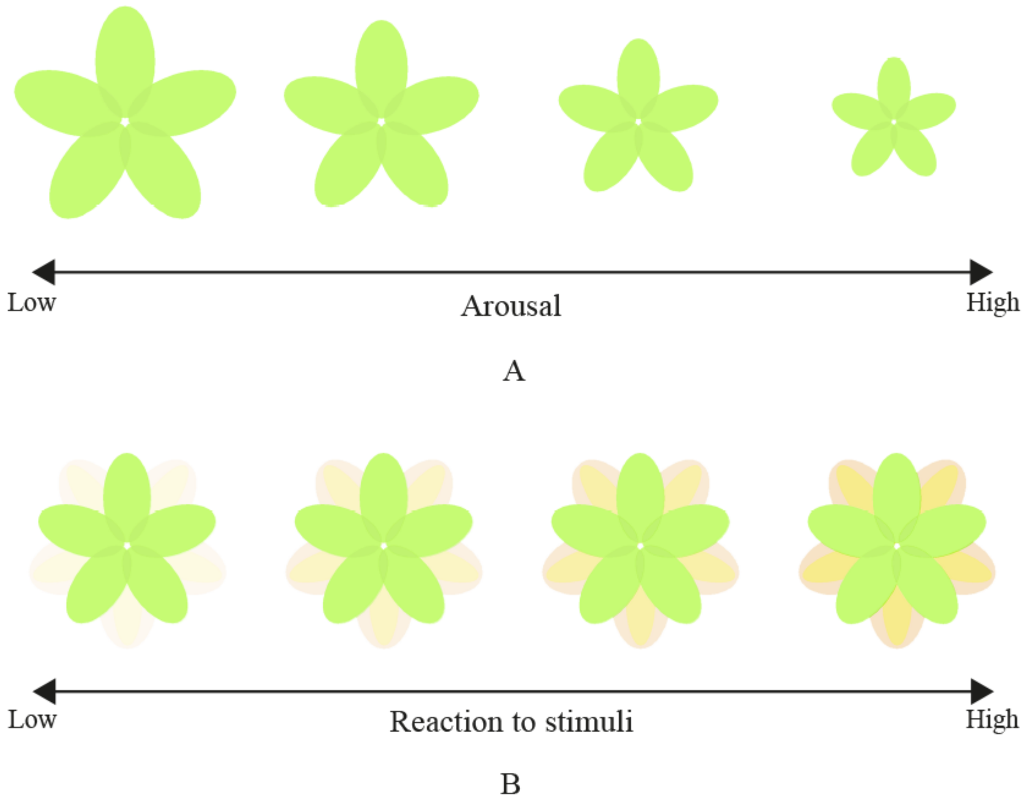


Figure 12.2 The visualization of the flower in the Flower app.
Panel 12.2A: The flower's size decreases when the arousal level increases, and vice versa.
Panel 12.2B: The additional flower petals become more visible if the reaction to stimuli becomes stronger.

phase, the Bioresponse system was not only used during the observations but also during daily care moments of the caregiver's selection. That is, caregivers were encouraged to use the system for 90 minutes during each shift they worked with the participating client during the intervention phase.

12.2.4 Procedures

During each video and physiological signal recording, the client and caregiver were requested to perform three activities. A short recap of the two activities relevant to the measures of joint attention and affective mutuality is provided here (all activities are described in detail in Chapter 11, page 134). A structured play moment, taking inspiration from the Early Social Communication Scale tasks (Mundy et al., 2003), aimed to evaluate joint attention behaviors. This task, with a duration of 10 minutes, requested the caregivers to present three toys (each for 2–3 minutes) to the client followed by singing songs for/with the client for approximately 2–3 minutes. Affective mutuality was evaluated using the Three Boxes procedure, in which the dyad is presented with three boxes each containing a different kind of toy. The caregiver is instructed to guide the client through 15 minutes of play, starting with box 1 and finishing with box 3. The caregiver can divide the time over the three boxes as he/she deems fit.

12.2.5 Instruments

Joint Attention

A self-developed observation manual, specifically designed for the observation of adults with visual and severe or profound intellectual disabilities, was used to measure joint attention during the play moment (see appendix E on page 212 for the coding manual). This manual —based on the joint attention scale for blind infants (Bigelow, 2003), the joint attention scale for toddlers with autism (Naber et al., 2007), and the joint attention behaviors in persons with profound intellectual and multiple disabilities (Neerinckx & Maes, 2016) — contains three scales (preliminary behaviors (PB), basic joint attention behaviors (BJA), and associated joint attention behaviors (AJA)). The PB scale has three subscales: “find objects”, “gestures towards objects”, and “gestures requesting interaction”. The BJA scale consisted of the subscales “pointing,” and “focusing attention”. The AJA scale has six subscales: “follow direction”, “show object”, “checking”, “labels”, “take”, and “give”. For each subscale, the occurrence and duration of the behavior are scored.

Five independent observers, bachelor’s students in Developmental Psychology at the Vrije Universiteit Amsterdam, scored the video recordings blind to the phase of the study and in random order using Noldus The Observer version 10.5 software (Noldus Information Technology, Wageningen, the Netherlands). After a short training on three videos, all videos were scored by two observers, who coded independently of each other, and the resulting scores were averaged for use in the analyses. The percentages of agreement on the frequency of PB, BJA, and AJA behaviors were 64.3%, 47.7%, and 55.3% respectively and 96.3% (PB), 89.7% (BJA), and 96.7% (AJA) for the duration of these behaviors. Cohen’s kappa was for the frequency .49 (PB), .17 (BJA), and .50 (AJA) and .95, .82, and .96 respectively for the duration.

Affective Mutuality

Affective mutuality was measured with the dyadic scale of the 24-month version of the National Institute of Child Health and Human Development (NICHD) scales, rated on a 7-point Likert scale (Brady-Smith, O’Brien, Berlin, Ware, & Brooks-Gunn, 1999). The dyadic scale has one subscale, “mutuality/connectedness”, that measures the synchrony, comfort, and mutual pleasure in the dyad’s interaction.

Four independent observers, master’s students in Developmental Psychology at the Vrije Universiteit Amsterdam, coded the video recordings of the Three Boxes procedure blind to the phase of the study and in random order. Prof. C. Schuengel, a registered NICHD trainer, Dr. M. Oosterman, and Prof. P.S. Sterkenburg from the Vrije Universiteit Amsterdam provided training for the independent observers. Each video was scored by two observers. Consensus was reached between two observers when the difference between the observers’ scores was two points or more. For scores with less than two points difference, the average scores were used for analysis purposes. In a similar study by Sterkenburg and Schuengel (2010), the intraclass correlation (ICC) for the observers for the dyadic scale was .94 with no observer drift. In the current study, the ICC for the dyadic scale was .92.

12.2.6 Analysis

The analysis procedure, consisting of two parts, was used for the three joint attention categories separately (PB, BJA, and AJA) as well as for the affective mutuality scores. Only observational data was used; the physiological data was only used as feedback for the caregivers during the intervention. The first part of the analysis was to visually inspect the trend in both the frequency and the duration of the behaviors. For each client, the regression line and the regression coefficient (RC) were calculated and the regression line plotted together with the scores of the 21 observations of PB, BJA, AJA, and affective mutuality. The trend was categorized as positive for an increasing regression line and positive RC, or as negative for a decreasing regression line and negative RC. The degree of positivity/negativity of the trend was classified as slight ($-0.5 > RC < 0.5$), moderate ($0.5 < RC < 5$ or $-5 > RC > -0.5$), or steep ($RC > 5$ or $RC < -5$).

The second part consisted of performing a Friedman's ANOVA test to control for a significant difference ($\alpha = .05$) between the baseline, intervention, and follow-up phases. The analyses are performed for each participant separately. As each phase existed of seven repeated observations, a repeated measure design was used. The non-parametric analysis, Friedman's ANOVA, was selected over the parametric analysis, the repeated measures ANOVA, because with only seven repeated measurements per dyad a repeated measures ANOVA is not reliably. After performing the Friedman's ANOVA test for each dyad separately, the results of the four participating dyads were combined in a meta-analysis, in which the natural logarithms of the p-value for each client were summed and multiplied by -2. P-values smaller than .005 were replaced with the value of .01, and changes in unexpected directions were replaced with the value .5 regardless of the actual value. The outcome followed a χ^2-distribution with the number of cases multiplied by two as degrees of freedom (de Weerth & van Geert, 2002).

12.3 Results

12.3.1 Joint Attention

Due to technical problems with the video files, two videos from Client A proved unusable for analyses and are, therefore, excluded. The Friedman's ANOVA test showed a significant difference for the frequency of BJA behaviors of Client B ($\chi^2 = 6.0$, $p = .05$) and the duration of AJA behaviors of Client A ($\chi^2 = 11.14$, $p = .004$). The decreasing trend in the duration of PB behaviors of Client B ($\chi^2 = 6.0$, $p = .05$) was also significant. No significant differences were found for Clients C and D (Table 12.3). Since Client A's p-value for the duration of AJA was lower than .005, this value was replaced by .01 in the meta-analysis. No replacements for unexpected directions were made, due to the Friedman's ANOVA test following a χ^2-distribution (which only provides a right-tailed test). The result from four clients combined was not significant.

The mean frequency of the observations per phase showed a substantial increase in PB behaviors for Client D (Table 12.4). Client C's mean frequency for BJA behaviors was lower in the intervention phase compared to the baseline and follow-up phases, while the mean duration for the intervention phase was higher than for the baseline and follow-up phases. Due to the moderate interrater agreement on the frequency of PB and AJA and the slight interrater agreement on the frequency of BJA behaviors, these results need to be interpreted with caution. The mean duration of PB behaviors for Clients A and C increased substantially in the intervention phase compared to the baseline phase. For Client A, this trend continued in the follow-up phase, while for Client C the mean duration decreased in the follow-up phase.

Visual inspection of the joint attention behaviors (Figure 12.3) of Client A showed a steep incline in the duration of PB and AJA behaviors with a regression coefficient (RC) of 13.43 and 13.02 respectively and a decline in BJA behaviors with an RC of -5.29. This trend was also reflected in the frequencies, although less pronounced. Client B's BJA behaviors increased in frequency (RC: 0.05), however, decreased in duration (RC: -1.18); while her AJA behaviors decreased in frequency (RC: -0.06) and increased in duration (RC: 0.35). Client C had a moderate increase in the duration of PB and BJA behaviors (RC of 3.7 and 0.84 respectively) with only a slight increase in frequency (PB: 0.13 and BJA: 0.09). Client D showed a moderate increasing trend for both frequency and duration in PB behaviors (RC of 0.68 and 0.88 respectively), but only a slight increase in BJA (RC frequency: 0.04 and RC duration: 0.2) and AJA behaviors (RC frequency: 0.15 and RC duration: 0.01).

12.3.2 Affective mutuality

One video from Dyad D is excluded from analyses as a result of failing recording equipment. The Friedman's ANOVA test and the meta-analysis results showed no significant differences in affective mutuality scores for the baseline, intervention, and follow-up phases (Table 12.3). For Clients B and C, the mean affective mutuality scores indicated a higher score for the intervention phase compared to the baseline and follow-up phases. The mean scores decreased from the baseline to the follow-up phase for Clients A and D (Table 12.4).

The visual inspection of the affective mutuality scores showed a positive trend for Dyad B during the intervention and follow-up phases (RC of 0.10 and 0.31 respectively) (Figure 12.4B). Dyad C's affective mutuality scores increased during baseline and intervention phases (RC of 0.29 and 0.06 respectively); however, decreased in the follow-up phase (Figure 12.4C). The scores of Dyad A displayed a positive trend for the baseline phase (RC: 0.18); however, a decreasing trend during the intervention (RC: -0.10) and follow-up phases (RC: -0.06) (Figure 12.4A). Dyad D showed a negative trend for baseline and intervention phases (RC of -0.30 and -0.05 respectively), but an increasing trend for the follow-up phase (RC: 0.10) (Figure 12.4D).

12.4 Discussion

The results from this randomized multiple baseline study were inconclusive; however, fluctuations in the client's joint attention behavior and the dyad's affective mutuality between caregivers and adults with S/PID were observed. Due to the interrater agreement on the frequency being slight for BJA behaviors and moderate for PB and AJA behaviors, while the interrater agreement on the duration was almost perfect for all behaviors, it is likely that the duration scores better reflect the effects of the Bioresponse system on the joint attention scores than the frequency scores. Considering the duration behaviors only, two clients showed a significant difference

Scale		Client A		Client B		Client C		Client D		Combined	
		Frequency	Duration	Frequency	Duration	Frequency	Duration	Frequency	Duration	Frequency	Duration
Preliminary Behaviours (PB)	χ^2	2.0	2.57	5.04	6.0	0.92	3.71	1.14	2.57	9.12	14.88
	df	2	2	2	2	2	2	2	2	8	8
	p	0.37	0.28	0.08	0.05	0.63	0.16	0.57	0.28	>0.25	<0.10
Basic Joint Attention (BJA)	χ^2	0.67	0.0	6.0	1.14	0.52	1.14	2.92	2.92	10.1	5.2
	df	2	2	2	2	2	2	2	2	8	8
	p	0.72	1	0.05	0.57	0.77	0.57	0.23	0.23	>0.25	>0.25
Associated Joint Attention (AJA)	χ^2	1.14	11.14	3.08	0.8	0.13	2.71	4.08	0	8.42	12.74
	df	2	2	2	2	2	2	2	2	8	8
	p	0.57	0.004	0.21	0.67	0.94	0.26	0.13	1	>0.25	<0.25
		Dyad A		**Dyad B**		**Dyad C**		**Dyad D**		**Combined**	
Affective Mutuality	χ^2	0.52		0.07		3.00		2.39		5.97	
	df	2		2		2		2		8	
	p	0.77		0.96		0.22		0.30		>0.25	

Table 12.3 Friedman's ANOVA test and meta-analysis (four clients combined) results of comparing the baseline, intervention and follow-up phase

12

		Baseline		Intervention		Follow-up	
		Frequency	**Duration**	**Frequency**	**Duration**	**Frequency**	**Duration**
Scale	Client	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Preliminary Behaviors (PB)	Client A	2.86 (1.46)	356.19 (188.52)	3.79 (1.87)	401.75 (314.43)	4.21 (1.25)	512.14 (136.99)
	Client B	5.64 (1.86)	119.80 (83.87)	3.29 (2.84)	69.04 (121.82)	3.43 (2.64)	42.06 (40.52)
	Client C	6.07 (5.62)	60.20 (60.63)	8.43 (1.52)	175.07 (102.58)	6.86 (5.27)	110.68 (95.15)
	Client D	3.64 (2.39)	12.45 (7.37)	6.43 (7.17)	9.67 (8.81)	11.50 (7.81)	24.55 (14.82)
Basic Joint Attention (BJA)	Client A	3.46 (2.48)	185.63 (175.16)	3.21 (2.46)	120.38 (106.52)	4.43 (3.06)	124.37 (89.35)
	Client B	6.64 (2.69)	110.37 (141.75)	3.86 (2.25)	41.48 (36.37)	6.43 (4.67)	80.95 (61.22)
	Client C	10.64 (9.06)	84.95 (64.38)	8.21 (2.80)	106.47 (45.23)	11.36 (7.14)	100.53 (70.13)
	Client D	0.29 (0.57)	0.90 (1.63)	0.00 (0.00)	0.00 (0.00)	0.71 (1.47)	3.15 (8.14)
Associated Joint Attention (AJA)	Client A	15.64 (8.54)	160.32 (96.71)	18.36 (9.56)	217.78 (146.15)	19.29 (4.44)	388.47 (106.85)
	Client B	1.64 (1.68)	5.20 (13.75)	0.43 (0.45)	2.75 (6.28)	0.50 (0.65)	6.93 (18.32)
	Client C	1.36 (1.57)	6.98 (9.60)	1.29 (1.63)	2.65 (4.74)	1.36 (2.32)	7.71 (19.99)
	Client D	1.29 (0.81)	4.69 (11.82)	0.43 (0.79)	1.12 (2.42)	2.93 (3.62)	3.65 (6.40)
		Mean (SD)		Mean (SD)		Mean (SD)	
Affective Mutuality	Client A	5.17 (0.47)		4.68 (0.67)		4.32 (1.28)	
	Client B	2.89 (1.19)		3.61 (1.32)		3.25 (1.70)	
	Client C	2.00 (0.71)		3.04 (1.08)		2.43 (1.46)	
	Client D	2.78 (1.17)		2.58 (1.34)		1.75 (0.60)	

Table 12.4 Average frequency and duration of Joint Attention and Affective Mutuality behaviours per phase

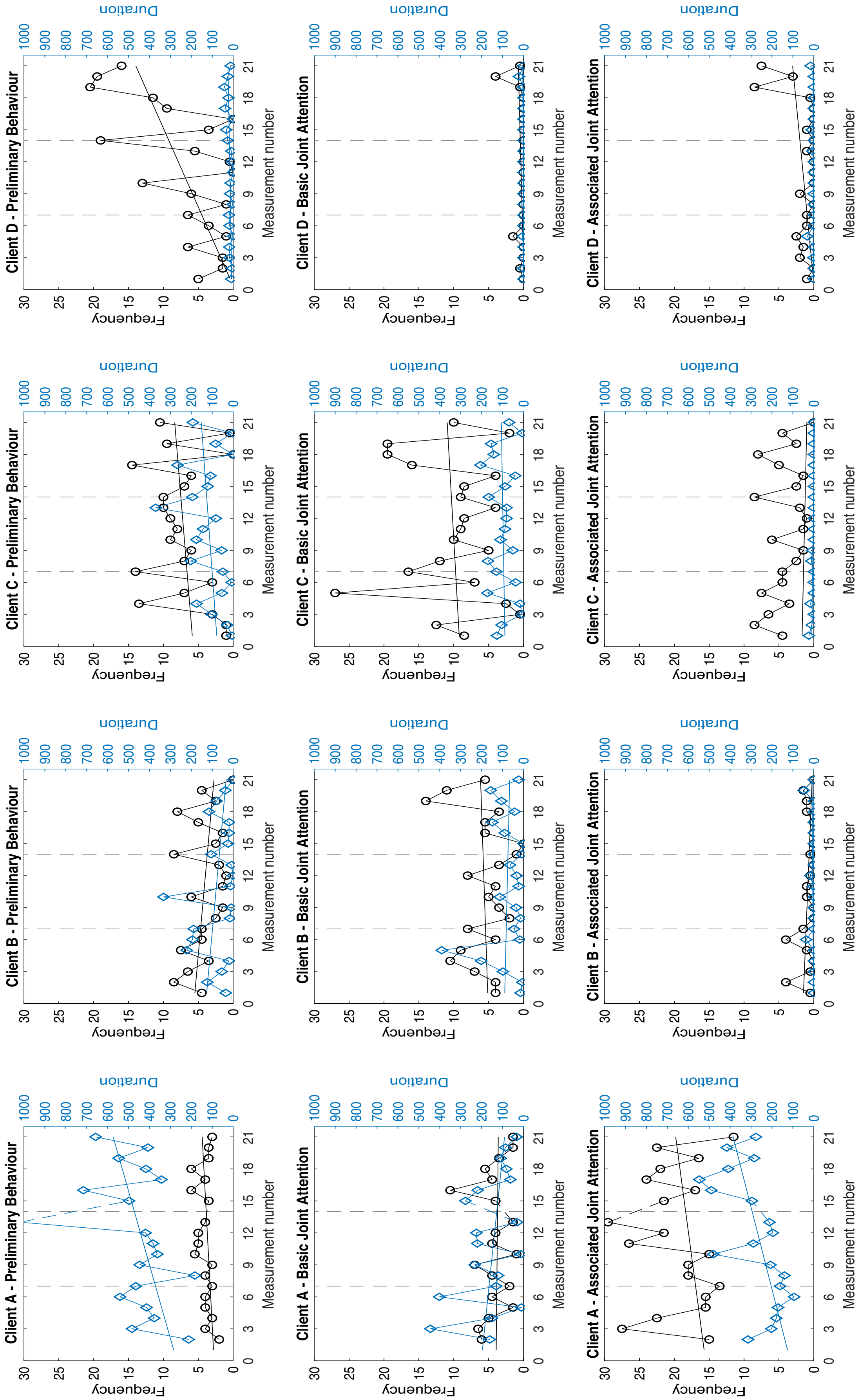


Figure 12.3 Frequency (black) and duration (blue) of Preliminary Behaviors (top), Basic Joint Attention behaviors (middle), and Associated Joint Attention behaviors (bottom).

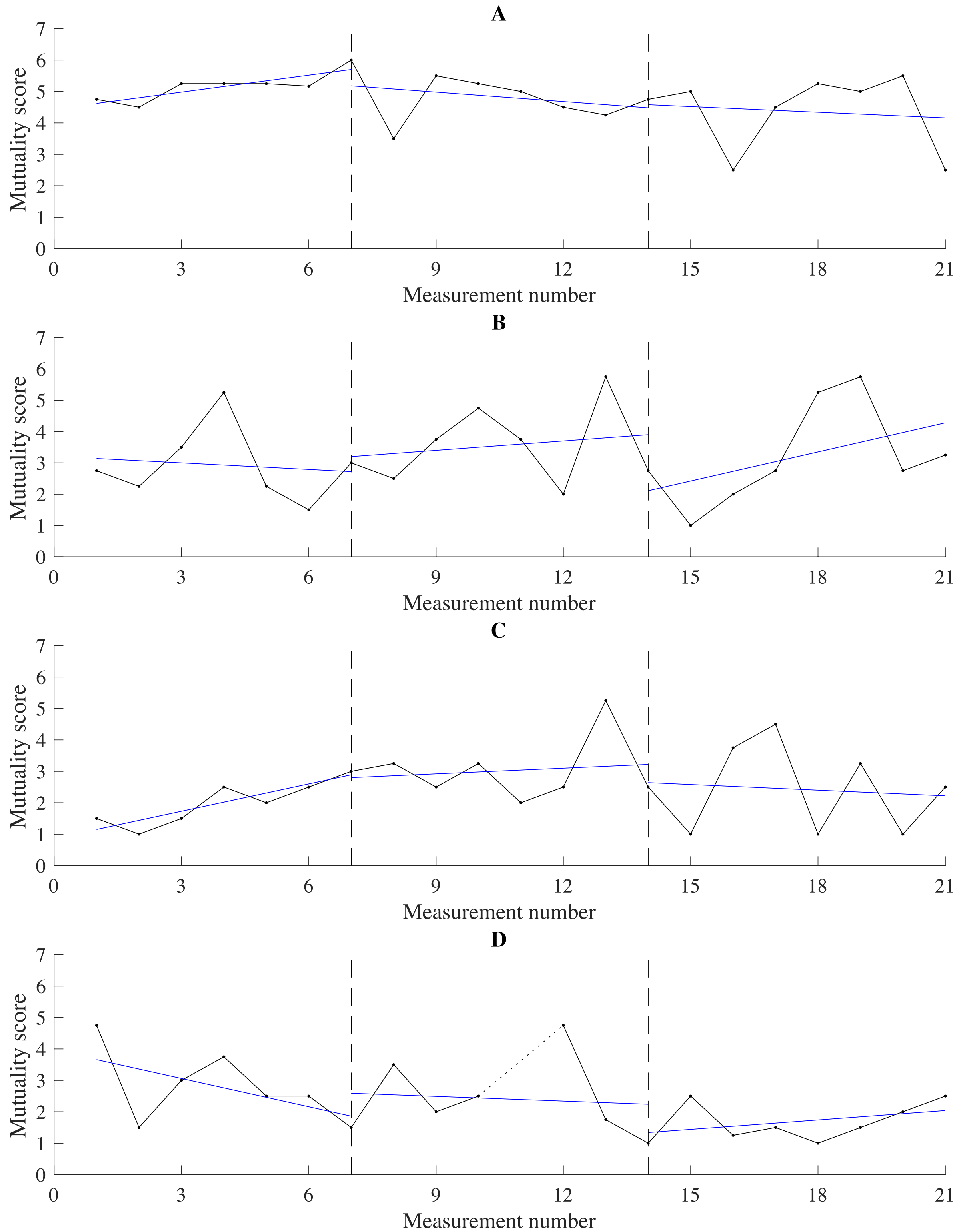


Figure 12.4 Regression lines for Affective Mutuality scores

between phases on one subscale of joint attention: one client showed a significant increase and one client a significant decrease. Looking at the mean durations, for every subscale one client had a higher mean duration during the intervention phase than during the baseline phase, and two clients had a higher mean duration during the follow-up phase than during the intervention phase. However, none of the clients showed a positive trend on all three subscales, neither did one subscale improve for all four clients. Visual inspection of the data shows an increasing trend over all phases for two clients on PB behaviors and for one client on AJA behaviors. The affective mutuality scores revealed no significant differences, but in the visual inspection of these scores, a positive trend for two client–caregiver dyads was visible during the intervention phase. A slightly negative trend was present for the other two dyads. For one of the two dyads with a positive trend in the intervention and one of the two dyads with a negative trend in the intervention, the trend in the follow-up phase was positive. The other two dyads showed a slightly negative trend in the follow-up phase.

No conclusions can be drawn from the intervention study due to the intervention not working as intended. After finishing the data collection, the discovery was made that the flower in the app did reflect skin resistance (SR) and not skin conductance (SC). This caused the flower's behavior to reverse. Due to a technical error, the displayed size of the flower had not changed during the intervention. Therefore, misinterpretation of the flower's feedback as a result of the inversed behavior of the flower was prevented. The second form of feedback provided by the flower — the display of additional petals that reflect reactions to stimuli in the environment — did function. Therefore, caregivers did receive some feedback; still, no conclusions can be drawn. A more detailed discussion on the technical errors and the consequences for the results is provided in Chapter 11, page 142.

The interrater agreement on the frequency of the joint attention scales was slight for the BJA scale (0.17) and moderate for the PB (0.49) and AJA scale (0.50), while the agreement on the duration was an almost perfect agreement (PB: 0.95, BJA: 0.82, and AJA: 0.96) (McHugh, 2012). This difference suggests that an episode of joint attention behavior was differently interpreted by the observers as either a single occurrence or several occurrences of joint attention behavior, while the total duration of this behavior was scored equally. As the analysis was conducted with average scores, the expected influence of the disagreement between observers is expected to be minimal. However, for future uses of this joint attention scale, the frequency scoring of the joint attention behaviors should receive specific attention.

12.5 Lessons learned

Although the intervention did not work as intended, new insights for the development and research of monitoring systems were gained. A summary of the lessons learned in the current study is provided here (for a full discussion of the lessons learned please see Chapter 11, page 142):

- Having a tool that supports the detection and interpretation of the client's communicative behavior might in itself stimulate caregivers to reflect on their behavior towards the client.

- A check protocol to test the flower's feedback on functioning as intended is advisable for future studies (e.g., using a breathing exercise and an arithmetic exercise as a test situation).
- A more strict video recording protocol — for example, holding the tablet in front of the video camera and visibly pressing one of the colored buttons at the start and end of the measurement — is required to ensure reliably synchronizing between the video recording and the sensor measurement.
- This study has proven that repeated measurements of the measures for joint attention and affective mutuality are feasible without overloading clients and that caregivers are willing to invest the time and effort in repeat measure studies. Repeated measurements might reveal interesting results with regards to factors that cause fluctuations in these results over time.

12.6 Conclusion

Due to the measurement of SR instead of SC and the app's failure to adapt the flower's size in real-time, no conclusions can be drawn with regards to the effect of the Bioresponse system on the client's challenging behavior and the dyad's affective mutuality. However, this study may have provided some potential positive indicators. All clients showed a positive trend on at least one of the three subscales for joint attention behaviors, although the trends were not consistently positive on all three subscales for one client neither for all clients on one subscale. Two out of four client-caregiver dyads showed a positive trend for affective mutuality scores; the other two dyads displayed a negative trend. A repetition of the research with a larger sample is required for drawing conclusions on the effect of a Bioresponse system on the quality of interaction. However, this study has suggested that the Bioresponse system may have the potential to positively influence the quality of interaction between professional caregivers and adults with visual and severe or profound intellectual disabilities.

Chapter 13 Conclusion

13.1 Introduction

The previous chapters have described the development and evaluation of a monitoring system that supports professional caregivers in their interaction with clients with visual and severe/profound intellectual disabilities (V-S/PID). In the first section of this chapter, the results are summarized and the research questions, as formulated in Chapter 1 (page 4), are addressed. The limitations of the research involving the monitoring system are discussed in section 13.3. Finally, this chapter is concluded with the implications of this thesis on design and research.

13.2 Conclusions

13.2.1 First objective: the development of the monitoring system

The aim of this thesis was twofold. The first objective was to develop a monitoring system that can support parents and professional caregivers in their interaction with persons with V-S/PID, which was formulated into the research question:

1. *How to design a monitoring system that supports parents and professional caregivers in their interaction with persons with visual and severe/profound intellectual disabilities (V-S/PID)?*

At the start of the project, little was known about how to design a monitoring system to support the interaction between caregivers and persons with V-S/PID. Theories on physiological signal monitoring as a measure for (emotional) arousal and stress — taken from research areas like affective computing and biofeedback — formed the basis for the project. Studies from Kobayashi, Nunokawa, and Ooe (2009), Lima et al. (2012), Lima, Silva, Amaral, Magalhães, and de Sousa (2013), and Vos et al. (2012), and Vos, De Cock, Petry, Van Den Noortgate, & Maes (2013) had proven that physiological signal monitoring can be a measure for (emotional) arousal for persons with V-S/PID. However, a monitoring system that could be applied in the daily environment of persons with V-S/PID was not yet available.

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An iterative design process (following the spiral model of Boehm (1988)) has been used to develop a monitoring system for the daily environment of persons with V-S/PID (Figure 13.1). Each iteration went through four steps: (1) defining the design requirements, (2) transforming the design requirements into a concept design, (3) creating a prototype of the concept design, and (4) evaluating the prototype. This iterative process allowed for learning along the way, for involving potential users, and for evaluating assumptions and design requirements. The process has resulted in three iterations of a monitoring system (of which the design processes

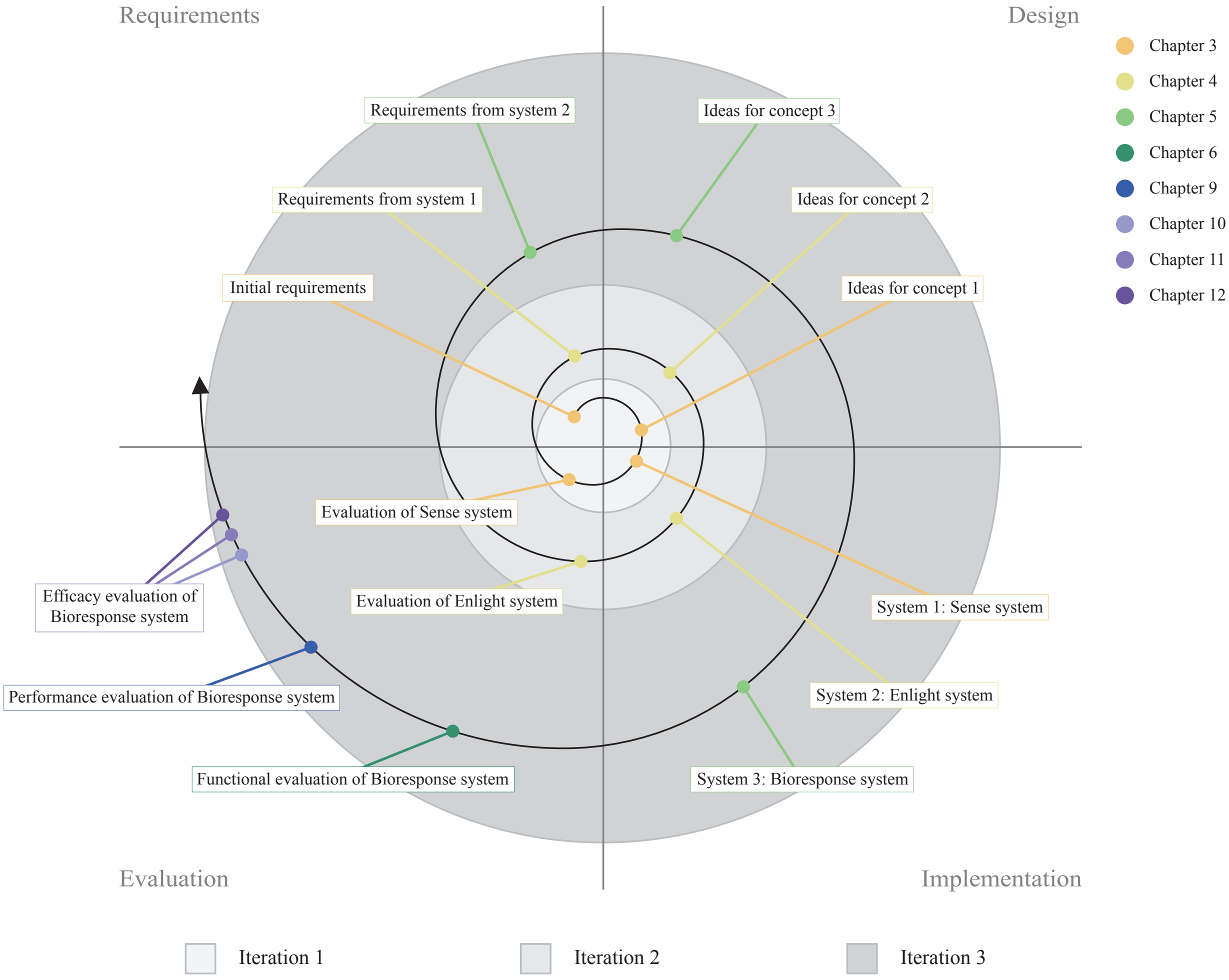

Figure 1.1 Spiral model of the iterative approach to answering the research questions.

are described in chapters 3, 4, and 5).

1a. What are the design requirements for a monitoring system that is used in the daily environment of persons with V-S/PID?

Although the development of the monitoring system is an ongoing process and more requirements will be added in the future, the requirements for a monitoring system that are currently known, are:

(1) the system needs to support parents/caregivers during the interaction with their child/client (Chapter 3, page 21);
(2) the system needs to trigger a response from parents/caregivers when their child/client is not able to attract their attention (Chapter 3, page 21);
(3) the system should be portable and wireless in both its measurement and its feedback of the physiological signal(s) (Chapter 4, page 44);
(4) the system should be unobtrusive, comfortable, and pleasant/everyday looking (as opposed to looking like a medical aid) (Chapter 4, page 44);
(5) the system's feedback should not be perceivable for the child/client as children/clients with V-S/PID are prone to develop behavior to trigger the occurrence of the feedback

(Chapter 4, page 44);
(6) the system should be shareable between key persons in the child's/client's life (Chapter 4, page 52);
(7) the system should be available to multiple professional caregivers both during one shift and over multiple shifts (Chapter 5, page 56);
(8) the system should be operable with a minimum number of actions to prevent adding to the high workload of the caregivers (Chapter 5, page 56).

So far in the development of the monitoring system, the Bioresponse system — consisting of a skin resistance sensor (Shimmer, Dublin, Ireland), a sensor sock (developed by M. Croes and K. Frederiks), and an Android application (developed by M. Croes, L. Vork, and P. Peters) — fits these design requirements best.

1b. Can technologies, developed to measure (emotional) arousal for persons without disabilities, also measure (emotional) arousal for persons with V-S/PID?

The ability of physiological signals, specifically electrodermal activity, to reflect (emotional) arousal is evaluated with two iterations of the monitoring system. First, the Sense system validated that a skin conductance (SC) sensor could reflect arousal for children with Prader–Willi syndrome (Chapter 3). Although the SC sensor could not differentiate between positive and negative emotional arousal, the SC signal did increase upon presentation of a stimulus. More peaks or peaks with higher amplitudes were observed during moments of high arousal compared to low arousal moments. As peaks in the SC signal could be matched with the stimuli, the SC sensor can likely provide information about the child's reaction to the interaction. Secondly, an evaluation with the Bioresponse system confirmed SC can reflect (emotional) arousal for adults with V-S/PID (Chapter 9). Few fluctuations in the SC signal did correspond to a low number of observed changes in the client's behavior; while frequent fluctuations related to frequently observed changes in the client's behavior.

1c. What are the (requirements for the) components that compose a monitoring system for persons with V-S/PID?

A design guideline (presented in Chapter 6, page 70), created together with dr. H. IJzerman, has listed the following components and their requirements:
(1) an external device; this device should preferably be portable, wireless, and offer sufficient storage and visualization capabilities (examples: smartphone or tablet);
(2) a sensor; the sensor should be small, unobtrusive, comfortable, wireless, and highly accurate (example: smart clothing);
(3) an operating system; the operating system should preferably be open-source and widely used in the selected external device (example: Android);
(4) a communication method; the communication method should have a direct connection to the sensor to prevent data loss and should be widely used in the selected external device (example: Bluetooth Low Energy);
(5) sensor-specific software; the sensor-specific software should preferably be open-source and shared with other researchers (example: GitHub platform for sharing software).

A requirement that should be considered when selecting each component is the component's privacy warrant.

1d. What are the requirements for marketing a monitoring system for persons with V-S/PID?

A guideline for marketing a monitoring system (presented in Chapter 6, page 72) has listed the following advice:

(1) Create a multidisciplinary team; a multidisciplinary team is required as the process of developing and marketing covers several fields of expertise. Knowledge of the environment of persons with V-S/PID and their needs and wishes, knowledge of research, knowledge of design processes and manufacturing processes, knowledge of software development, knowledge of marketing and distribution, and knowledge of communication are required to be able to develop, produce, and sell a monitoring system.

(2) Draw up a collaboration agreement; drawing up a collaboration agreement is a time-consuming process, but a vital one. In this agreement, objectives of the collaboration and the role of each partner to achieve these objectives, confidential knowledge, the usage and sharing of the knowledge, and licenses for (part of) the developed monitoring system are defined.

(3) Keep the products separate; products developed for research have different aims than commercial products. Each product has its own set of design requirements. Separating the two products by name, form, and functionality will improve communication and prevent confusion for users.

13.2.2 Second objective: the evaluation of the monitoring system

The second objective was to validate the effectiveness of the monitoring system with caregivers and clients with V-S/PID, which was formulated into the research question:

2. *What are the effects of a monitoring system that supports parents and professional caregivers in their interaction with persons with visual and severe/profound intellectual disabilities (V-S/PID)?*

The third iteration — the Bioresponse system — was used to validate the effects of the monitoring system. This validation consisted of an experiment with non-disabled subjects, a pilot study with professional caregivers and adults with V-S/PID, and a randomized multiple baseline study with professional caregivers and adults with V-S/PID.

2a. How accurately can the monitoring system measure (emotional) arousal?

In an experiment with 22 students of the Eindhoven University of Technology, a Support Vector Machine (SVM) algorithm (designed and performed by dr. Z. Di) classified the sensor signal into representing stress or relaxation. This classification resulted in an accuracy of 99%. In comparing the sensor signal to the participant's self-report measure (using a second SVM algorithm), an accuracy of 95% was achieved. Although these accuracy predictions cannot be extrapolated to other test situations, these predictions do show that the feedback the Bioresponse system provides to caregivers is accurate.

2b. What is the relationship between (emotional) arousal as measured by the monitoring system and the (emotional) arousal as observed in the client's behavior?

A pilot study involving two adults with V-S/PID and their professional caregiver has compared the sensor measurements of the Bioresponse system to behavioral observations. An average agreement between the sensor measurements and the behavioral observations of 32.4% was found. As the challenges to interpret the client's subtle communicative behavior are the reason for the development of a monitoring system, a low agreement is to be expected. Mean skin conductance (SC) values were expected to increase for increasing arousal levels (as defined in the behavioral observation scale); however, this increase was not consistently observed. For two measurements, the mean values did even decrease for increasing arousal levels, and in two measurements, a fluctuation in mean values was observed for increasing arousal levels. Visual inspection of the SC signal has shown that few fluctuations in the SC signal did correspond to a low number of observed changes in the client's behavior; while frequent fluctuations related to frequently observed changes in the client's behavior. However, a steady increase or decrease from the start to the end of the measurement was observed in the SC signal that was not present in the behavioral observations.

2c. What is the social validity of the monitoring system for professional caregivers?

As part of the randomized multiple baseline study with four adults with V-S/PID and their caregivers, the Bioresponse system's social validity was evaluated using the Social Validity Scale. This questionnaire was filled out by caregivers at the start of the study and after having used the Bioresponse system for 12 weeks. Two caregivers perceived the Bioresponse system more positively after having used the system; however, two caregivers did perceive the system more negatively after usage. All caregivers rated the usage of the Bioresponse system as more difficult than they had expected at the start of the study. Two caregivers were positive about the training in the use and interpretation of the Bioresponse system that was provided at the start of the study. The other two caregivers showed a negative trend in their rating of the training. All caregivers indicated that the changes in their behavior towards the client were less than they had expected upon starting the study.

2d. What is the effect of the monitoring system on the interaction between professional caregivers and persons with V-S/PID as measured by the caregiver's sensitive responsiveness, the client's joint attention behavior, the client's challenging behavior, and the dyad's affective mutuality?

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No conclusions can be drawn with regards to the effect of the Bioresponse system on the interaction between professional caregivers and persons with V-S/PID since the intervention study did not work as intended. The Flower app reflected skin resistance (SR) instead of skin conductance (SC). Due to a technical error, the flower's feedback was only partial: the size of the flower did not alter, but the additional flower petals did reflect the client's reactions to stimuli in the environment. The outcomes of the randomized multiple baseline study did show that the Bioresponse system has the potential for positively influencing the quality of interaction between professional caregivers and persons with V-S/PID.

Three out of four caregivers showed a positive trend in sensitive responsiveness during the intervention phase; the fourth caregiver had a slightly negative trend during the intervention. Two out of four caregivers had a higher mean sensitive responsiveness score for the intervention phase compared to the baseline and follow-up phases; the two other caregivers had a lower mean score for the intervention phase compared to the baseline and follow-up phases. Furthermore, all clients showed a positive trend on at least one of the three subscales for joint attention behaviors. Two clients showed a decreasing trend on one subscale of the challenging behavior scales and three clients had a lower mean duration of one subscale of challenging behavior. For both the joint attention scales and the challenging behavior scales, these trends were not consistently positive on all three subscales for one client neither for all clients on one subscale. Finally, two out of four client-caregiver dyads showed a positive trend for affective mutuality scores; the other two dyads displayed a negative trend.

13.3 Limitations

Throughout the studies described in this thesis, the sample size has been a limitation. In the evaluation of the Sense system (chapter 3) and the Enlight system (chapter 4), the target group was parents and their child with Prader–Willi syndrome (PWS), aged 6–24 months. As approximately twelve children each year are born with PWS in the Netherlands (Expertisecentrum Prader–Willi syndroom, 2019), the sample size is bound to be small. To expand the group of potential participants, a switch in target group was made to persons with severe multiple disabilities. There are approximately 10,000 persons with severe multiple disabilities in the Netherlands. Around 90% of them live in a home provided by an organization specialized in care and support for persons with intellectual disabilities and/or additional impairments (Vereniging Gehandicaptenzorg Nederland, 2019). However, due to the relatively small number of persons with severe multiple disabilities in the Netherlands, they — and their caregivers — can be overcharged with requests for participation in studies; therefore, small samples are more common in this area of research. Even in the experiment involving subjects without disabilities, the sample size appeared to be limiting as the analysis included more sophisticated methods of machine learning. The effects of this small sample could be countered with an algorithm that systematically increased the sample size (SMOTE algorithm, Chapter 8, page 101). Future research should create a careful balance between wanting a large sample size and not overcharging the participants, and between the time required for studies with large sample sizes and the use of available algorithms to systematically increase the sample size.

The randomized multiple baseline study (described in chapters 9, 10, 11, and 12) was limited by a failing intervention, which was only discovered after finishing the data collection. The feedback provided to caregivers during the intervention was reversed (reflecting SR, the opposite of the intended SC), potentially leading to the misinterpretation of the client's communicative behavior. Due to a technical error, the feedback remained constant (meaning it did not change during the intervention), which has prevented misinterpretation of the feedback. For a more detailed discussion of this limitation, please see Chapter 11, page 142.

13.4 Lessons learned

The three design iterations, the design evaluations, and the accuracy and effect studies have generated insights relevant for both research and design involving monitoring systems. Even the randomized multiple baseline study has provided the chance to use the Bioresponse system for an extended period of time in the context of care organizations and thereby generated lessons learned relevant for future studies and design developments.

One of those lessons learned is to have the same expectations of the technology for both researchers and participants. Although the Bioresponse system is already a developed product, its development will continue. With each step in the process and with each study, more knowledge regarding monitoring systems has been generated. We now have a list of design requirements and essential components for a monitoring system, and we now know that the system is accurate for subjects without disabilities, but also that this technology does work similarly for clients with V-S/PID. At the same time, new questions did arise with each step in the process. In the evaluations, parents/caregivers might have been unaware of where in the process of development the Bioresponse system was and which questions were still unanswered. As a result, the expectations of the system could have exceeded the system's abilities.

As said before, the development of the Bioresponse system will continue and this development is necessary for the system to be accepted and actually used by clients with V-S/PID and their caregivers. If research and development stop when the effectiveness of a product has been proven, the product risks to be ill-fitting to its environment. Technology keeps evolving, thereby causing apps that are currently well functioning to become less efficient with each update of the operating system and in the end to become inoperable. Continuing the development will ensure an up-to-date system and a good fit to the daily practice, and support gathering more in-depth knowledge simultaneously. This will also benefit the care organizations. These organizations support and enable the research to improve the well-being of their clients and employees. They have invested their time and effort in participating in the research. When this research results in products that they can use, they will get a return for their investment as well.

Finally, there are insights regarding the practical execution of the study. During the multiple baseline study, the sensor sock's design was slightly changed by lengthening the connecting wires between the fabric electrodes and the snap fasteners. Some of the socks did not stretch enough when the participating client put on the sock and caused the wire to snap. The socks and the sewing manual (Appendix A, page 174) were adapted accordingly. Another point of insight, that was only discovered after finishing the data collection, was a need to label the socks. Some of the graph plots of the recorded skin resistance data were not entirely as expected compared to previous graphs from the same participant. A possible cause could be a defect in the sock. As the socks did not have an identifying mark and there were multiple socks of the same size, this could not be checked.

13.5 Research Implications

The Bioresponse system has been developed to support the interaction between caregivers and persons with V-S/PID. The intended use for the Bioresponse system is in the daily environment of persons with V-S/PID where the presence of interfering stimuli will be inevitable and in situations where caregivers are uncertain about interpreting their client's communicative behavior. The validation of the Bioresponse system has revealed a need for understanding the physiological signal better.

The pilot study with adults with V-S/PID (Chapter 9, page 117) indicated the situation wherein the physiological data is recorded may influence the usefulness of the system's feedback. The measurement situations in this pilot study were either from standardized methods or from daily situations encountered in the client's environment. As a result, little variation in arousal was observed in both the sensor measurements and the behavioral observation. In other studies of Vos et al. (2012, 2013; wherein known pleasant and unpleasant situation were compared), Lima et al. (2012, 2013; wherein specific stimuli were selected to trigger a reaction), and Vandesande et al. (2020; wherein the child was comforted by a stranger or by the parent), situations were selected wherein large differences in arousal were to be expected. As a result, these studies did observe variation in arousal in both the sensor measurements and the behavioral observation. Neither the studies described in this thesis, nor the studies from Vos et al. (2012, 2013), Lima et al. (2012, 2013), and Vandesande et al. (2020) considered the situations that align with the intended use of the Bioresponse system. This is likely due to the unpredictability of when these situations occur and the difficulty to compare a large variety of situations. Future research should address the situations of intended use to gain more insight into the usefulness of the Bioresponse system's feedback and in how the Bioresponse system should be used (for example, should the Bioresponse system be started whenever the situation in question arises or should the Bioresponse system be started minutes before this situation is expected to occur?).

Next to considering the situation in which the data is recorded, analyzing the data with machine learning methods might allow for a better understanding of the physiological data. Unsupervised machine learning methods could support the discovery of patterns in the physiological data. In unsupervised machine learning, the data is divided over a training set and a test set. Using the training set, an algorithm classifies the data into a preset number of clusters. Based on the parameters found in the training set, the test set is classified over the same clusters, thereby verifying the previously found parameters. As a result, the physiological data will be grouped based on patterns the algorithm detected in the data. These groups could then be compared to behavioral observations in an attempt to discover what caused this pattern in the physiological data. The question remains whether machine learning will be a beneficial solution for the data of the Bioresponse system, as it is specifically developed to solve complex problems with multiple variables that cannot be visualized in a 2D or 3D plot. The physiological data used for the Bioresponse system exists of only one variable: skin conductance (SC). Although, multiple features can be calculated from this one variable (e.g., SC level, SC responses, mean, standard deviation, kurtosis, or skewness), machine learning might not reveal new insight compared to visual inspections and standard analysis.

A better understanding of the data could result in a better design of the system. One of the design requirements found in the development of the monitoring system (the system needs to trigger a response from parents/caregivers when their child/client is not able to attract their attention (Chapter 3, page 21)) requires a better understanding of the physiological signal. Providing an alert to attract the caregiver's attention based on the measured signal depends on a threshold value for this signal. When the sensor signal exceeds this threshold value, the monitoring system will alert the caregivers. As the range of measured values for electrodermal activity varies per person, this threshold value will be different for each person as well. This threshold value may also vary for one person based on the temperature of the environment or on whether the person has recently eaten or exercised. Future research is needed to define what the threshold should be, to find a value for this threshold, and to discover whether this threshold value should be adaptable to changes in temperature and activities.

Machine learning might again be a tool for finding these threshold values, even when these values are not constant. Supervised machine learning creates a model based on the data of a training set. The training set includes the physiological data and a variable that provides each data point with a label (e.g., no alert or alert). The model is verified with a test set. The test set does not contain the labels. The model will, based on the parameters found with the training set, provide each data point with a label. For the bioresponse system, supervised machine learning could be used to discover the threshold value for an alert, but it could also be transformed into a self-learning system. A self-learning system adjusts the initial model based on the information it gathers while in use. Feedback could be provided by caregivers on whether or not the alert was correct. In case the alert was incorrect, the model will adjust its parameters and prevent an incorrect alert in the future. One concern for the use of a supervised learning method is that it takes behavioral observation as golden standard. Research has shown that behavioral observation can be reliable to interpret emotions, but also that observations can differ largely between caregivers and that the interpretation may depend on the context wherein this behavior is shown (Vos et al., 2013). The Bioresponse system has specifically been developed to support caregivers in interpreting this subtle communicative behavior. Future research — likely including both participants with V-S/PID and non-disabled participants — is needed to determine whether a self-learning system is feasible, reliable, and even whether it is desirable.

13.6 Design Implications

The development of a monitoring system that supports the interaction between caregivers and persons with V-S/PID has proven that the best design solution for such a monitoring system is the combination of smart clothing and a mobile application (app). However, the development is not finished and will continue with more integration of the technology into garments. The vision for the future of the monitoring system is to completely integrate the technology into a garment so that the garment can directly connect to a mobile application.

One benefit of smart clothing and an app is that these elements fit in the client's environment without requiring adjustment. Clients with V-S/PID can become stressed when encountering novel situations or objects, and may need a period of time to adjust to these novel situations and objects. Standard sensing equipment is bulky, uncomfortable, and unfamiliar to clients. Smart clothing can offer comfort and familiarity to clients since it feels and looks like normal clothing, but has integrated electronics, computers, and algorithms that provide the clothing with the capability to measure and/or react (Gepperth, 2012). Furthermore, smart clothing can offer comfort to parents and caregivers since it can provide them with additional information without visually distinguishing the client from his/her peers. Being able to see the sensor may prompt undesired questions or attention to the sensor that takes attention away from the client.

Another benefit is that smart clothing and an app do not add any additional actions for the client and add only minimal extra actions for the caregiver. Smart clothing can be put on while dressing in the morning or when getting ready for bed when information during the night is preferred. In this way, putting on the sensor becomes part of the client's existing daily routines. This does not burden the client with having to develop new routines or have irregular disruptions of the daily routine when the monitoring system is not used at set moments. It also lessens the burden on caregivers of not having to put on/take off a sensor whenever the information from the system is desired. All that is required is that the caregiver connects the app wirelessly to the smart clothing. Adding to the benefits is that the information from the monitoring system is available to all key persons in the client's life. Since the client is wearing the sensor, the sensor is available wherever the client is. The app can easily be made available to the key persons in the client's life (e.g., family and friends coming to visit, caregivers over multiple shifts, staff from activity centers). When desired, even persons who are not in regular contact with the client (e.g., the doctor or the clinical psychologist) could be offered access to the additional information without troubling the client with physically having to connect the sensors.

This vision poses some technical challenges. Smart clothing requires the integration of electronics, computers, and algorithms. The comfort from clothing comes from the clothing being soft, flexible, and fitting to the body's shape. Electronics and computers are usually made of hard, inflexible materials and the size of the components may lead to a bad fit for the body's shape. With current technological advances, the components are rapidly becoming smaller and smaller, and are being specifically developed for wearable applications. Many advantages can already be achieved through smart textiles; for example, conductive yarns can replace the wired connections between components. However, designing smart clothing for clients with V-S/PID may add some additional, possibly conflicting challenges. For example, as caregivers have a high workload, they do not have time for charging the smart clothing's batteries after every usage. Therefore, the technology integrated into smart clothing should be efficient and include long-lasting batteries. This may be in conflict with the requirement that the integrated components are as small as possible. Small batteries often are less powerful and do not last as long.

As stated above, smart clothing requires components' materials to become softer and more flexible. This holds especially true for persons with V-S/PID. Some persons with V-S/PID are highly sensitive to touch. Caregivers have often responded to the Bioresponse system with anecdotes of attempting to measure physiological measures using activity trackers with clients with V-S/PID, but the client refusing to wear the bracelet. Other caregivers have expressed concerns because their client was known for not wanting to wear any socks. For clients with V-S/PID to accept smart clothing, the smart clothing must resemble regular clothing as close as possible without hard or unflexible elements. Furthermore, a range of smart clothing (e.g., a sock, a shirt, etc.) might be necessary to allow caregivers to choose the best solution for their client.

To complicate the matter, the technology integrated into smart clothing should be robust. Clients with V-S/PID often show challenging behavior. One client, participating in the evaluation of the Bioresponse system, would occasionally engage in self-injuring behavior by kicking herself. During the evaluation, she was observed to accidentally kick the sensor. Furthermore, due to visual impairments, persons with V-S/PID may accidentally bump against furniture if the furniture has moved slightly. Thus, the technology used in smart clothing has to be robust to withstand the impact that may come from self-injuring behavior or accidentally bumping into furniture, meanwhile being soft, flexible, and fitting to the body's shape.

Another important aspect of smart clothing is hygiene. Smart clothing should be able to withstand regular washing. However, due to their high workload, caregivers do not have time to handwash the clothing or even to run a specialized program on the washing machine. Smart clothing should therefore be washable with other clothing at 60°C. This also requires that the integrated technology should either be waterproof or be easily removable (without adding multiple actions for the caregiver to do the laundry). Even if the technology is removed before putting the clothing in the washing machine, the technology should be waterproof. An often-heard concern from caregivers is the safety of using smart clothing when drinks are spilled on it, as caregivers indicate this happens often.

This vision also calls for a careful assessment of ethical concerns. One statement within this vision is that smart clothing can easily be connected to the smart phones of the client's key persons or other care professionals. This raises the question: who decides on who gets access to this data? Especially, since the client may experience challenges to communicate who the client thinks should or should not have access to this data. Also, the question of which data is collected should be raised. Technically, it may be possible to gather a large amount and a large variety of data. However, what data is required, what data is actually helpful, and what data is desirable or undesirable? Furthermore, who decides what is required, helpful, or (un)desirable? Another important concern is the interpretation of the data. Similar to behavioral observations, caregivers and key persons may have different interpretations of the provided feedback. This will be especially true when the provided information does not give information on the valence (positive, neutral, or negative value) of the measured arousal. These ethical questions cannot be answered by one person, but require the involvement of clients, their family and friends, caregivers, care professionals, care organizations, researchers, developers, manufacturers, and authorities to find the answers collectively.

The third iteration of the monitoring system, the Bioresponse system (described in Chapter 5), is closest design-wise to this design vision. It consists of a sensor, a sensor sock, and a mobile application. The sensor sock cannot be labeled as smart clothing, since the technology is not yet integrated. Instead, the sensor is attached to the client's ankle with a small strap. Technological advances are required before the sensor sock can be made into smart clothing; however, we hope and expect that future development will strive to get as close to the design vision as is possible.

APPENDICES

Appendix A Bioresponse sensor sock - Sewing instructions

Bioresponse sensor sock

Sewing Instructions

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Technische Universiteit Eindhoven University of Technology

Vrije Universiteit Amsterdam

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Table of Contents

Chapter 1 - Materials

Material list for 1 bioresponse sensor sock:
- 1 regular store-bought sock
- Conducting fabric
- Conducting thread
- 2 snapfasteners
- Regular fabric
- Regular thread
- Elastic band (optional)
- Velcro (optional)

Required tools:
- Needle
- Fabric scissors
- Tools to secure the snap-fasteners
- Sewing machine (optional)

The sensor sock is created from a regular store-bought sock. The size of the sock should correspond with the wearer's shoe size. Mind that the sock is not too tight as it might shrink a little as a result of washing at high temperatures. However, also do not buy a sock too large because it will effect the measurement if the fit of the sock is not correct.

The preferred material for the store-bought sock is a combination of cotton, polyamide, and elastane. Socks made of different materials can also be used; however, it is advised against the use of woolen socks, nylon socks, or socks with glitter, silver, or gold embellishments.

Shieldex® Technik-tex P130 is recommended for the conducting fabric, and for the conducting thread, Shieldex® 117/17dtex 2ply HC is advised. Other conductive materials can be used; however, make sure that the conductive fabric can stretch in two directions.

Additional materials required to create the bioresponse sensor sock are: snap-fasteners, a small piece of regular fabric (preferably cotton), and regular thread. It is optional to add elastic bands. Elastic bands ensure a better fit of the sock and thereby improve the measurements. They are helpful in situations where the wearer of the sock has to move his/her foot often and cannot wear a shoe over the sock. To create the elastic bands, velcro and elastic band are required.

The socks are sewn by hand. The elastic bands can be created by hand or with a sewing machine.

Chapter 2 - The fabric electrodes

2.1 The creation of the electrode

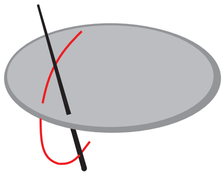
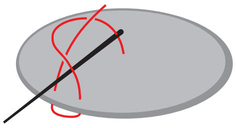
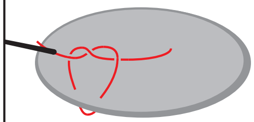
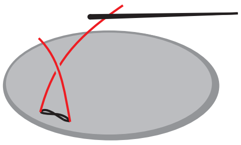
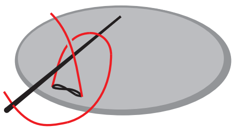
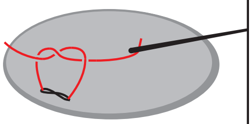
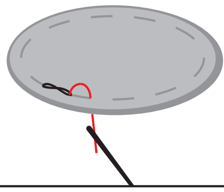
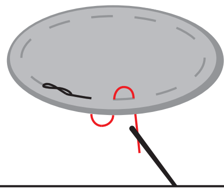
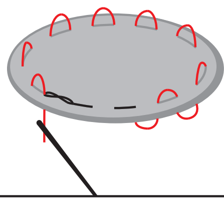
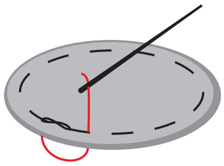
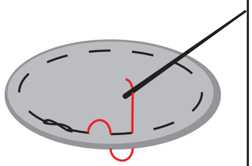
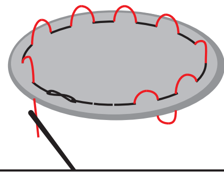
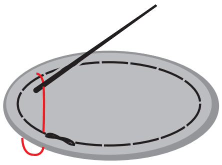
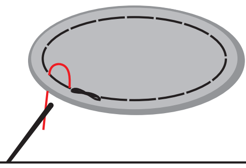
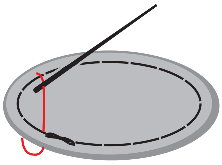
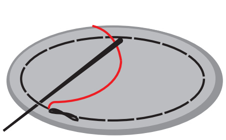
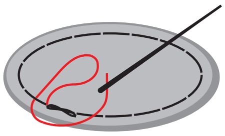
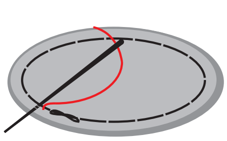
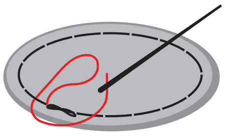
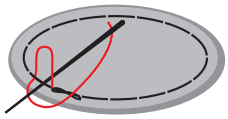
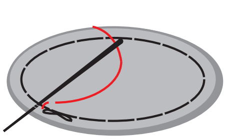
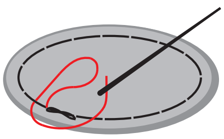
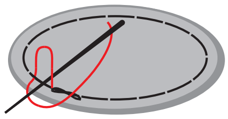
The electrode is created by drawing a circle on the conductive fabric and cut the fabric along the lines of the drawn circle. The electrode's diameter depends on the size of the sock (see Table 1 for the diameters; please mind that the sizes mentioned are European sock sizes). When creating multiple bioresponse sensor socks, it is advisable to create a template for the required diameter, for example out of cardboard, so the diameter can be repeatedly traced on the conductive fabric. Check whether the front and the back of the conductive fabric differ. If this is the case, trace the electrodes on the backside of the conductive fabric.

Table 1. electrode sizes based on the sock sizes

Sock size	**Size electrode**
Adults - size 36 to 53	Diameter: 2,6 cm
Children - size 28 to 35	Diameter: 2,0 cm
Children - size 13 to 26	Diameter: 1,0 cm

2.2 The application of the electrode

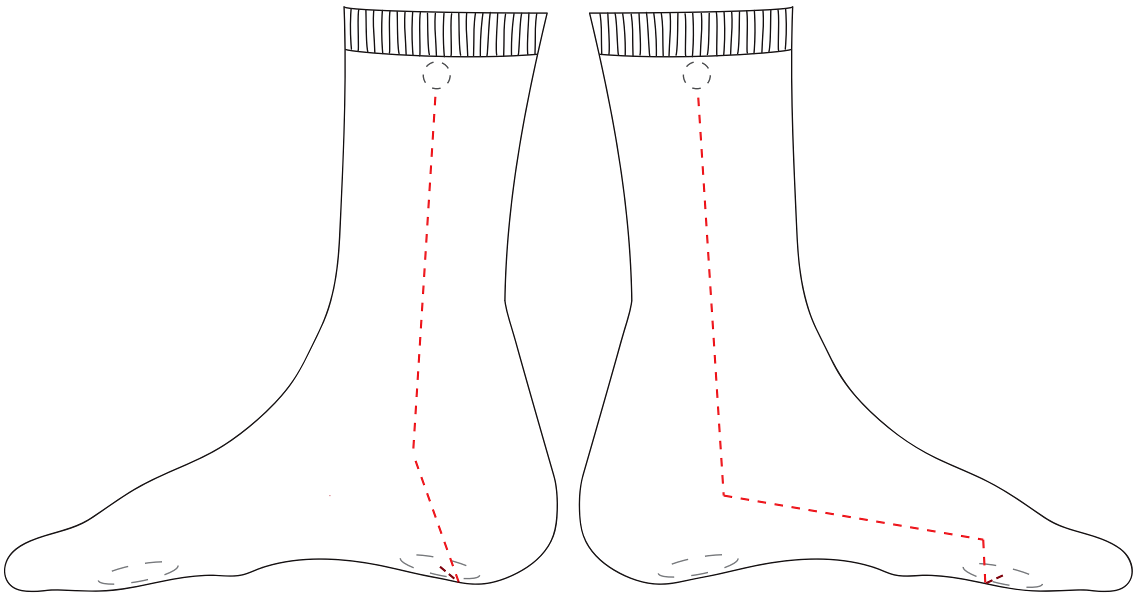
The electrodes are placed on the inside of the sock at the metatarsal (just under the toes) and the heel of the foot. To apply the electrodes turn the sock inside out and pin the electrodes to the sock with a sewing pin. The seams and folds of the sock can be used as guidance for placing the electrodes. Place one electrode underneath the seam at the toes and the other just past the fold of the heel. Make sure the electrode is placed flat before attaching the electrode to the sock (pleats in the fabric may result in erroneous measurements). The electrodes are applied with the conductive thread, however regular (non-conductive) thread can be used as well. Start the application of the electrode with a double knot (steps 1 and 2). Use a double running stitch to secure the sides of the electrode (steps 3 and 4), then tie off the thread using a double knot (steps 5 to 8).

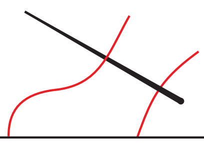
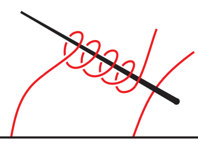
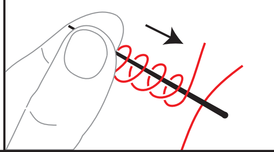
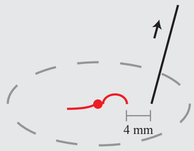
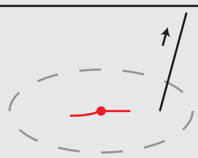
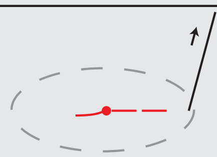
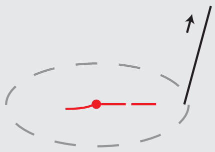
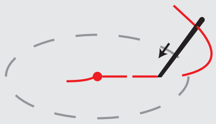
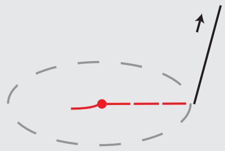
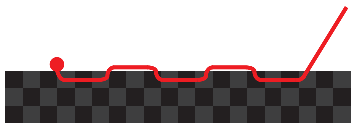
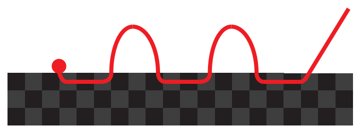
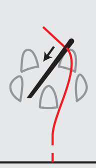
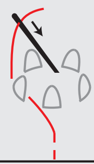
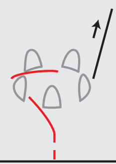
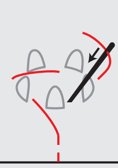
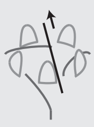
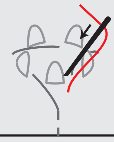
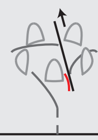
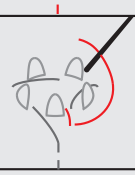
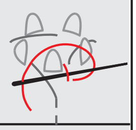
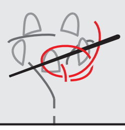
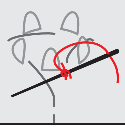
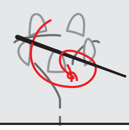
Steps			
Step 1: Secure the thread with a knot			
Step 2: Repeat the knot			
Step 3: Use a running stich to secure the electrode to the sock			
Step 4: Use a running stich in the opposite order than step 3			
Step 5: Loop the thread			
Step 6: Make a loop around the thread			
Step 7: Make a knot by pulling the thread through the loop			
Step 8: Repeat the knot			

Chapter 3 - The connecting wires

The electrodes are connected to snap fasteners (placed just below the hem of the sock) with the conductive yarn. To apply the connecting wires, turn the sock back. Tie a small knot in the conductive thread (step 1) and use three back stitches of approximately 4 mm wide to secure the thread to the electrode (step 2 to 4). Use a stoating stitch (picking up a few threads of the fabric with each stitch) to run the conductive yarn from the electrode to the hem of the sock (Step 5A). The conductive yarn must remain on the outside of the sock and may not go through the fabric of the sock. Before securing the conductive yarn to the hem of the sock, give the sock a good stretch. The yarn should ruffle a bit (Step 5B). This will ensure the sock can still stretch when the application of the wires is finished. Place the bottom half of the snap fastener just below the hem of the sock. The placement should be from the inside of the sock, so only the spikes are visible on the outside. Loop the conductive wire around the bottom part of the snap fastener (Step 6) and tie the thread off with a double knot (step 7).

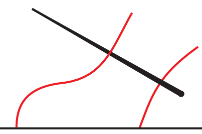
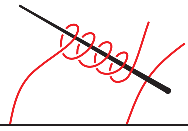
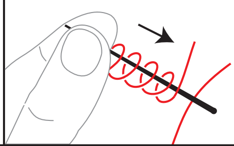
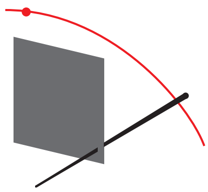
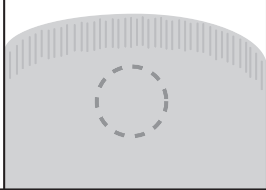
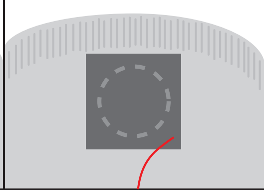
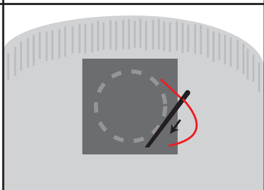
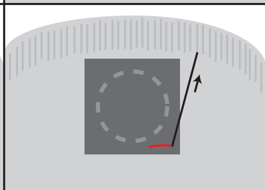
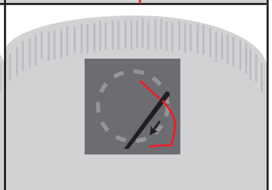
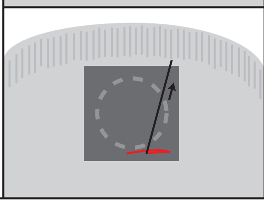
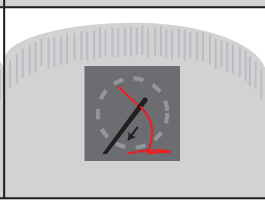
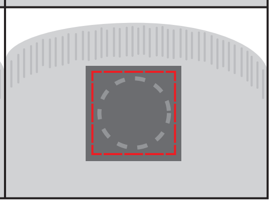
Step 5: Side view of sensor sock. Connect the electrodes to the snap fastener using a stoating stitch with the conductive yarn



Steps					
Step 1: Tie a knot in the conductive thread	Place the end of the thread over the needle 	Loop the thread around the needle 	Pull the looped part of the thread down to the end of the thread 		
Step 2: Secure the thread on the electrode with a back stitch. Make sure the thread is visible on the inside of the sock	Make sure the knot is on the outside of the sock 	Loop the thread around and make a stitch of about 4 mm wide 	Come back up about 4 mm from the previous stitch 		
Step 3: Make a second back stitch of approximately 4mm wide					
Step 4: Make a third back stitch of approximately 4mm wide					
Step 5: Use a stoating stitch to run the thread from the electrode to the hem of the sock	A 	B 			
Step 6: Loop the thread around the snap fastener					
Step 7a: Tie off the thread with a double knot.					
Step 7b: Tie off the thread with a double knot.					

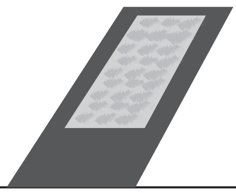
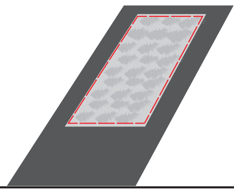
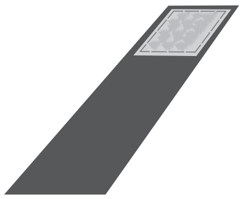
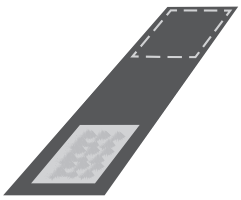
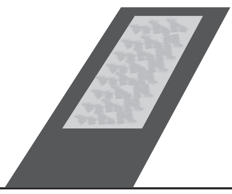
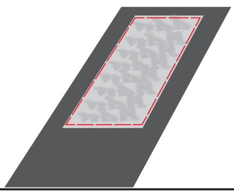
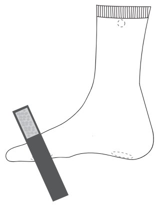
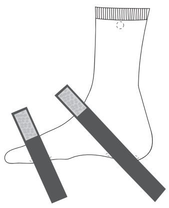
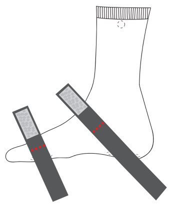
Chapter 4 - Finishing the sensor sock

To finish the sensor socks, the two parts of the snap fasteners need to be connected. For this step, follow the instructions that are provided with the snap fasteners. Usually, the snap fastener parts can be connected with the use of a hammer and a supporting tool or snap fastener pliers. In case multiple socks need to be created, the investment in a pair of pliers is recommended. The last step in the creation of the sensor sock is applying a small piece of non-conductive fabric (approximately 1 cm x 1 cm) over the back of the snap fastener (on the inside of the sock). Skin contact with the back of the snap fastener could cause noise in the recorded electrodermal data, which can be prevented with the non-conductive fabric. To apply this piece of fabric, tie a knot in a non-conductive thread (step 1). Pull the thread through the fabric from the back to the front of the fabric and place the fabric over the back of the snap fastener (step 2). Use a back stitch to connect the fabric to the sock (Step 3). Tie off the thread with a double knot (see Chapter 2, steps 6, 7, and 8). Optionally, add a small cross on the inside of the sock using a stoating stitch and different colored threads for each sock of the same size. In this way, the socks are identifiable. For example, if a data recording shows abnormalities, it can be tested whether these abnormalities result from a defect in the sensor sock.

Steps			
Step 1: Tie a knot in the thread	Place the end of the thread over the needle 	Loop the thread around the needle 	Pull the looped part of the thread down to the end of the thread 
Step 2: Pull the thread from the back through the fabric and place it over the back of the snap fastener			
Step 3: Use a back stitch to secure the piece of fabric to the sock			
			

Chapter 5 - The elastic bands (optional)

To ensure good skin contact with the fabric electrodes, elastic bands can be added to the sock. The addition of the bands is not recommended in combination with wearing shoes, as these bands may provide discomfort and shoes support good skin contact as well. To create the elastic bands, start with measuring the circumference of the foot at the location of the fabric electrodes. Cut two pieces of elastic: one with a length equal to the circumference at the metatarsal and one with a length equal to the circumference at the heel. Cut two pieces of Velcro with each piece containing both the hook (the rough side) and the loop (the soft side). Apply the loop side of the Velcro to one end of the elastic band (step 1) by using a sewing machine (preferred for a strong hold) or a back stitch (see chapter 3 steps 2, 3, or 4 for an explanation on the back stitch). Turn the elastic band over so that the soft side of the Velcro is on the back of the elastic band. Apply the hook side to the opposite end of the elastic band (step 2) by using a sewing machine or a back stitch. Pin the elastic band to the side of the sock with the loop side of the Velcro being at the top and facing forward. Sew the elastic band to the sock (step 3) using a sewing machine or a back stitch.

Steps			
Step 1: Apply the loop part of the Velcro to the elastic band			
Step 2: Apply the hook part of the Velcro to the elastic band			
Step 3: Sew the elastic band to the sock			

Appendix B Bioresponse system - User manual

GEBRUIKERSHANDLEIDING
Bioresponse systeem

1. VEILIGHEIDSVOORSCHRIFTEN

Let bij het aanbrengen van de sok, het enkelbandje en de armband erop dat de bandjes niet te strak zijn aangetrokken. Als er tijdens het gebruik van het systeem wordt ontdekt dat de bandjes te strak zijn aangetrokken, maak dan onmiddellijk de bandjes los en trek de sok, het enkelbandje en de armband uit.

Gebruik het systeem pas weer de volgende dag en houdt in de gaten of het ongemak dat de cliënt ervaart als gevolg van de bandjes die te strak hebben gezeten, weg trekt. Trekt dit ongemak niet weg, neem dan contact op met de arts van de cliënt.

Gebruik de sensor sok niet als:

- de sensor sok nat is geworden of nog vochtig is van het wassen
- de elektrodes, de drukknopjes of het garen los zitten
- de cliënt een geïrriteerde huid of open wondjes heeft. Gebruik de sensor sok ook niet als de cliënt wondjes op de zool van de voet heeft. Zorg er altijd voor dat wondjes, die afgedekt worden door de sok, bedekt zijn met een verband of pleister.

Gebruik de ShimmerTM sensor niet als:

- de sensor nat is geworden; laat de sensor minimaal 24 uur drogen
- de sensor in de oplader staat
- de sensor is beschadigd

Gebruik het enkelbandje niet als:

- de cliënt een geïrriteerde huid of (open) wondjes heeft
- de houder of het bandje is beschadigd
- de houder of het bandje nat is

Gebruik de Tempo DiscTM sensor niet als:

- de sensor nat is geworden; laat de sensor minimaal 24 uur drogen
- de sensor is beschadigd

Gebruik de armband niet als:

- de cliënt een geïrriteerde huid of (open) wondjes heeft
- de armband is beschadigd
- de armband nat is

2. DE ONDERDELEN VAN HET SYSTEEM

Het systeem bestaat uit de volgende onderdelen: de sensor sok (1), de band voor om de enkel (2), de Shimmer module (3), de Shimmer oplader (4), de verbindingsdraadjes (5), de tablet (6) en de tablet oplader (7). De onderdelen staan afgebeeld in onderstaande foto.

3. HET SYSTEEM OPSTARTEN

STAP 1: DE TABLET OPSTARTEN

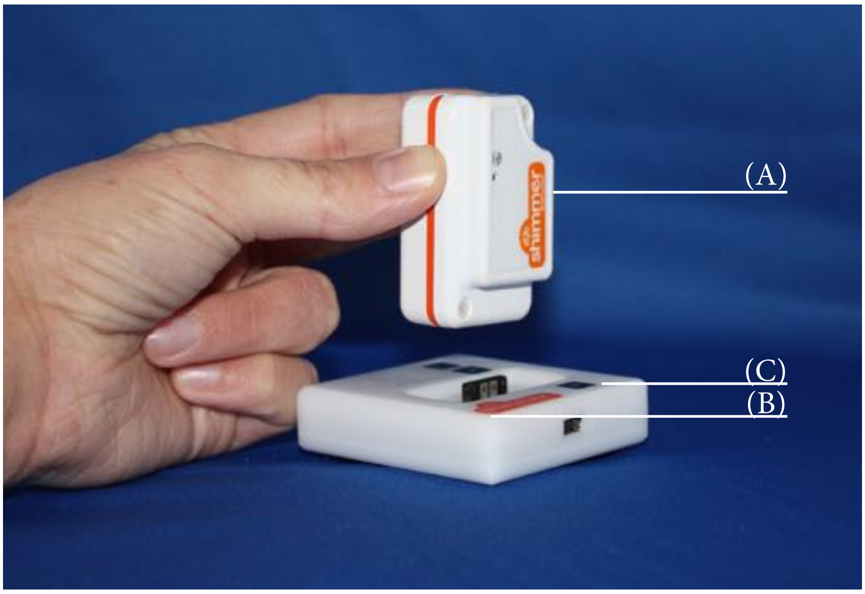
Schakel de tablet in door op de aan/uit knop aan de rechter zijkant (1) van de tablet te drukken. Laat de tablet rustig opstarten. De tablet heeft nog even tijd nodig om op de achtergrond een aantal programma's op te starten, ook al is het beginscherm (2) zichtbaar. Deze tijd kan gebruikt worden om de Shimmer module (Stap 2) op te starten.

(1) Locatie aan/uit knop op de tablet

(2) Het startscherm op de tablet

STAP 2: DE SHIMMER MODULE OPSTARTEN

Om de Shimmer module aan te zetten, heeft u de Shimmer module en de Shimmer oplader nodig. De oplader hoeft geen stroom te krijgen. Plaats de Shimmer module met de uitstekende kant (A) naar voren op de oplader, die zo moet staan dat de tekst zich in de linkerhoek (B) bevindt. De Shimmer module kan maar op één manier op de oplader geplaatst worden, dus let goed op of de Shimmer module en de oplader op dezelfde manier staan als in afbeelding 3. Er is geen kracht nodig om de Shimmer module op de oplader te plaatsen, dus forceer dit niet.



(3) Het plaatsen van de Shimmer module op de oplader

Druk op de kleine vierkante knop in de rechterhoek van de oplader (C). Als het lampje in de aan/uit knop (C) groen gaat branden, staat de Shimmer module aan. De Shimmer module kan nu van de oplader afgehaald worden.

4. HET SYSTEEM AANBRENGEN

STAP 1: DE SHIMMER MODULE PLAATSEN IN DE BAND

Zorg ervoor dat de Shimmer module aan staat. Plaats de Shimmer module in de band voor om de enkel. Forceer dit niet, maar duw de Shimmer module zachtjes op zijn plaats. Het plaatsen van de Shimmer module gaat een beetje stroef, maar hierdoor blijft de Shimmer module tijdens het dragen van de band goed op zijn plaats zitten.

De eenvoudigste methode om de Shimmer module te plaatsen gaat als volgt: plaats het linkerdeel van de Shimmer module (met het uitstekende deel naar boven) in de houder. Houdt de rechterkant van de Shimmer module met uw duim tegen de achterkant van de houder gedrukt. Duw nu met uw wijsvingers de Shimmer module gelijkmatig naar beneden (4). Voor meer uitleg, bekijkt u ook het instructiefilmpje. Hierin wordt de plaatsing van de Shimmer module voorgedaan.

(4) Het plaatsen van de Shimmer module in de houder

STAP 2: DE VERBINDINGSDRAADJES IN DE SHIMMER MODULE PLAATSEN

Sluit de verbindingsdraadjes aan op de contactpunten van de Shimmer module. De contactpunten bevinden zich aan de onderkant van de Shimmer module (5). Beide draadjes kunnen in beide contactpunten geplaatst worden. Er zit geen volgorde in het plaatsen van de draadjes.

STAP 3: DE SENSOR SOK AANDOEN

Trek de cliënt de sensor sok aan. Zorg ervoor dat de sok goed op zijn plaats zit. Maak de bandjes van de sok (6) om de voet vast met het klittenband. De bandjes moeten goed aansluiten om de voet, maar trek ze niet te strak aan! Het comfort van de cliënt staat voorop.

LET OP !!: De bandjes om de voet kunnen afknellen, trek deze dus niet te strak aan! Controleer de bandjes iedere keer dat de sok gebruikt wordt!

(5) De verbindingsdraadjes in de Shimmer module plaatsen

(6) De bandjes om de sok

(7) De band over de sok plaatsen en vastmaken

STAP 4: DE BAND OMDOEN

Doe de band om de enkel van de cliënt en sluit de band met het klittenband (7). Het maakt niet uit of de kleren van de cliënt over of onder de band zitten. Als de kleren van de cliënt onder de band zitten, let er dan wel op dat de drukknoopjes van de sensor sok vrij blijven. Zorg dat de band stevig op zijn plaats zit, maar trek de band niet te strak aan! Het comfort van de cliënt staat voorop.

LET OP !!: De band om de enkel kan afknellen, trek deze dus niet te strak aan!
Controleer de band iedere keer dat de band gebruikt wordt!

STAP 5: DE VERBINDINGSDRAADJES VASTMAKEN AAN DE SENSOR SOK

Aan het boord van de sensor sok bevinden zich twee drukknoopjes. Klik de verbindingsdraadjes vast op de drukknoopjes (8). Beide draadjes kunnen op beide drukknoopjes geplaatst worden. Probeer te voorkomen dat de draadjes elkaar kruisen.

(8) De verbindingsdraadjes vastklikken aan de sensor sok

(9) Het beschermhoesje van de tablet vouwen

STAP 6: DE TABLET PLAATSEN

Vouw de voorzijde van het beschermhoesje zodat de tablet recht op kan staan (9). Plaats de tablet in de buurt van de cliënt, zodat de tablet goed zichtbaar is. Let er bij het neerzetten van de tablet op dat het niet in de weg staat voor de cliënt. Voor meer informatie over het opstarten van de Flower app, zie hoofdstuk 4 op pagina 13.

5. DE FLOWER APP OPSTARTEN

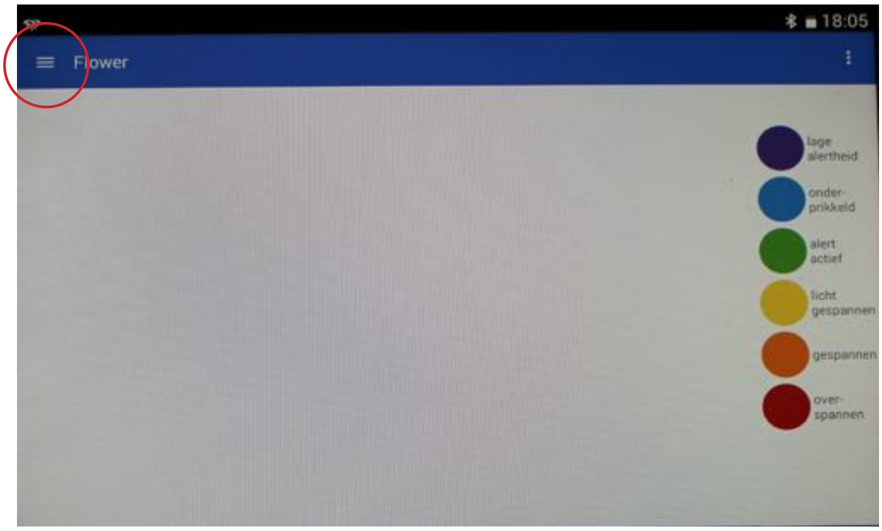
STAP 1: START DE APP
Ontgrendel het scherm van de tablet door met uw vinger over het scherm te vegen. Tik op het icoontje van de Flower app om deze app op te starten (10).

(10) Het icoontje van de Flower app

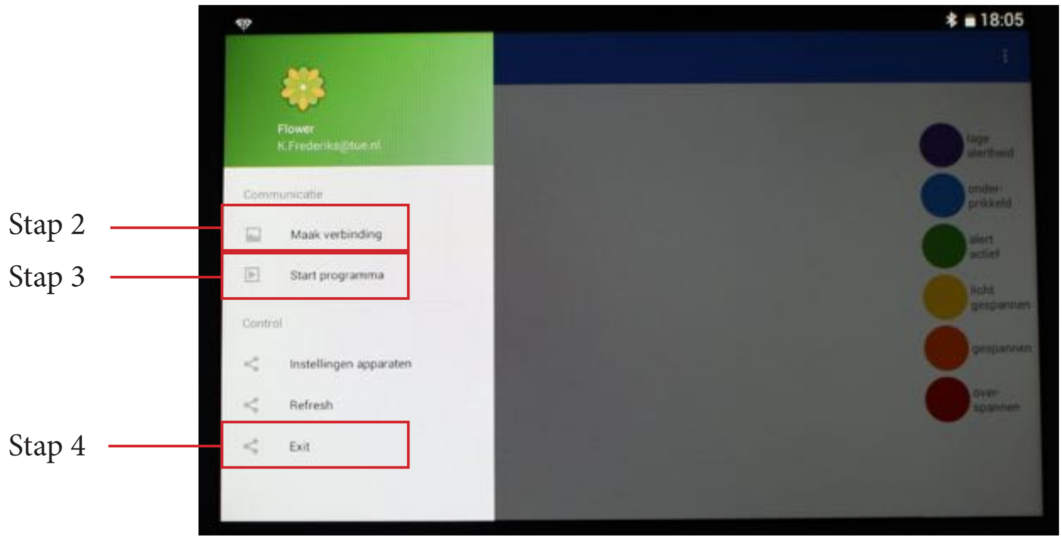
STAP 2: MAAK VERBINDING MET DE SENSOR

Tik op de menu-knop (11), links boven in het scherm en selecteer 'Maak verbinding' in het menu (12). Onder in het scherm verschijnt een informatiebalk: 'Verbinding maken ...'. Wacht totdat de informatiebalk 'Verbinding maken gelukt' verschijnt. Het programma kan nu gestart worden.

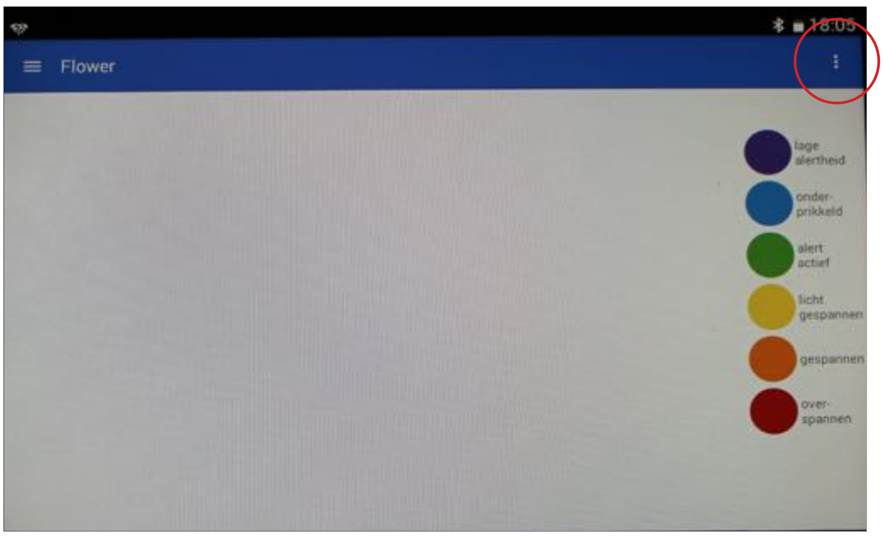
Als de informatiebalk 'Geen verbinding' verschijnt, doorloop stap 2 opnieuw. Blijft de informatiebalk 'Geen verbinding' na enkele pogingen terugkomen, controleer dan het volgende:
- Staat de Shimmer module aan? Voor uitleg over het aanzetten van de Shimmer module: zie pagina 9.
- Is de Shimmer module opgeladen? Voor uitleg over het opladen van de Shimmer module: zie pagina 19.
- Is de accu van de tablet voldoende opgeladen (meer dan 17%)? Voor uitleg over het opladen van de tablet: zie pagina 19).



(11) De menu knop van de Flower app



(12) Het menu van de Flower app



(13) Het optie-menu van de Flower app

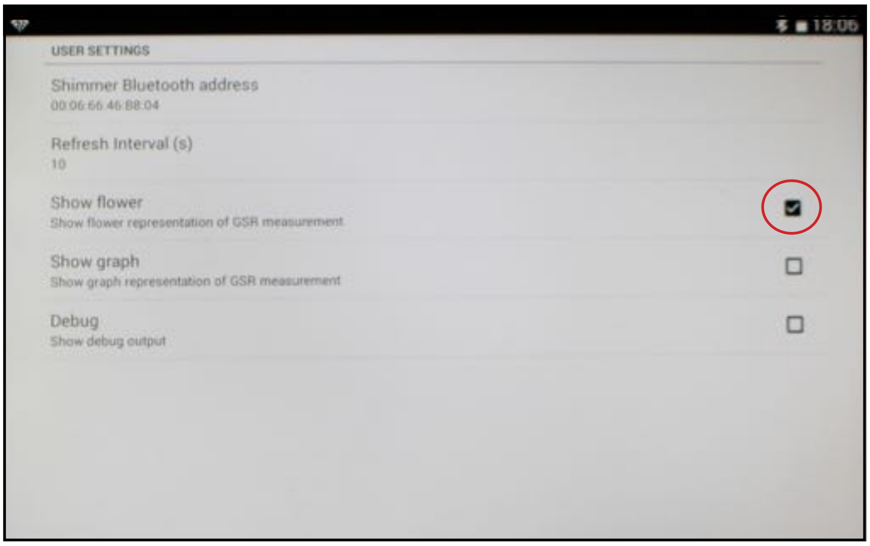
STAP 3: START HET PROGRAMMA

Als er verbinding is gemaakt met de Shimmer module, tikt u op de menu knop links boven in het scherm (11). Vervolgens tikt u op 'Start programma' (12). Onderin het scherm verschijnt een informatiebalk: 'Programma gestart' en er verschijnt een groene bloem op het scherm. U kunt het systeem nu gebruiken.

Als u geen bloem te zien krijgt, opent u dan het optie-menu (13), rechts boven in het scherm. Selecteer 'preferences'. Controleer of 'Show flower' aangevinkt is (14).

STAP 4: HET PROGRAMMA AFSLUITEN

Wanneer u het systeem niet meer nodig heeft, tikt u op de menu knop (11). Selecteer 'Stop programma'. Open opnieuw het menu en selecteer 'Verbreek verbinding'. Open het menu nog een keer en sluit het programma door 'Exit' in het menu te selecteren (12).



(14) Show flower is aangevinkt

6. HET SYSTEEM GEBRUIKEN

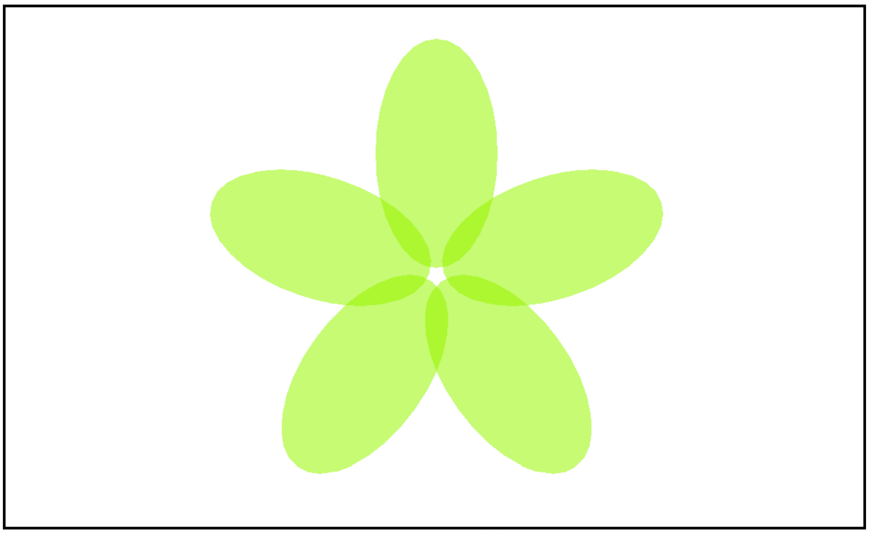
WAT BETEKENT DE BLOEM?

Als het systeem klaar is voor gebruik, zal een groene bloem zichtbaar zijn in het scherm van de tablet. Deze bloem zal van grootte veranderen. Hoe groter de bloem is, hoe meer arousal (emotie) de cliënt ervaart. Als de bloem klein is, betekent dit waarschijnlijk dat de cliënt rustig/ontspannen is. Wanneer de bloem groot is, ervaart de cliënt veel arousal. Dit kan meerdere betekenissen hebben. Veel arousal kan betekenen dat de cliënt erg gestrest is, maar het kan ook betekenen dat de cliënt iets erg leuk vindt. De bloem zegt dus niets over de soort emotie (positieve of negatieve emotie) die de cliënt ervaart.

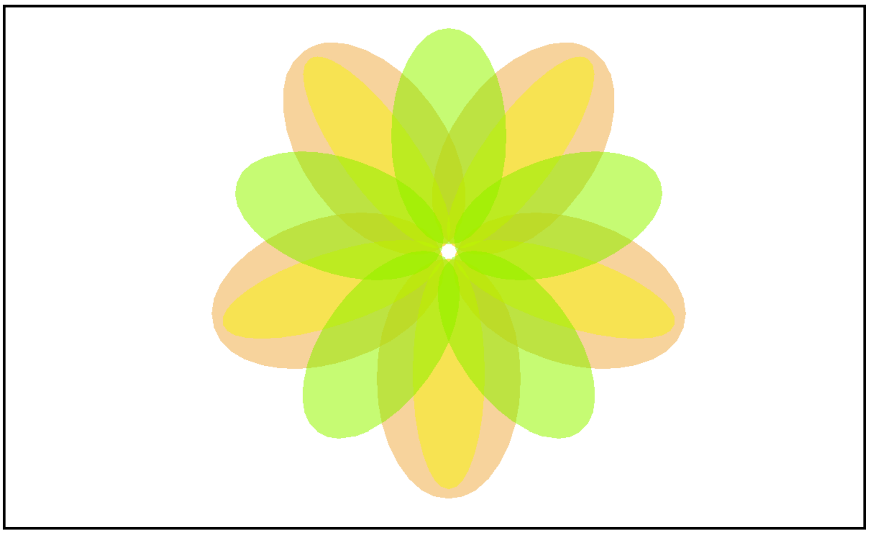
Naast de verandering van grootte, toont de bloem ook veranderingen in de hoeveelheid bloemblaadjes. Het aantal groene bloemblaadjes blijft gelijk, maar het aantal oranje bloemblaadjes verandert. Wanneer er geen of weinig oranje bloemblaadjes te zien zijn, reageert de cliënt niet sterk op prikkels uit zijn/haar omgeving. Dit betekent overigens niet dat de cliënt helemaal niet op prikkels reageert. De oranje bloemblaadjes geven alleen informatie over hoe sterk de reactie van de cliënt is. Veel oranje bloemblaadjes geven aan dat de cliënt sterk reageert op prikkels uit zijn/haar omgeving. Ook deze oranje bloemblaadjes kunnen niet aangeven of de cliënt de prikkels als leuk of als vervelend ervaart.

OBSERVATIES INGEVEN

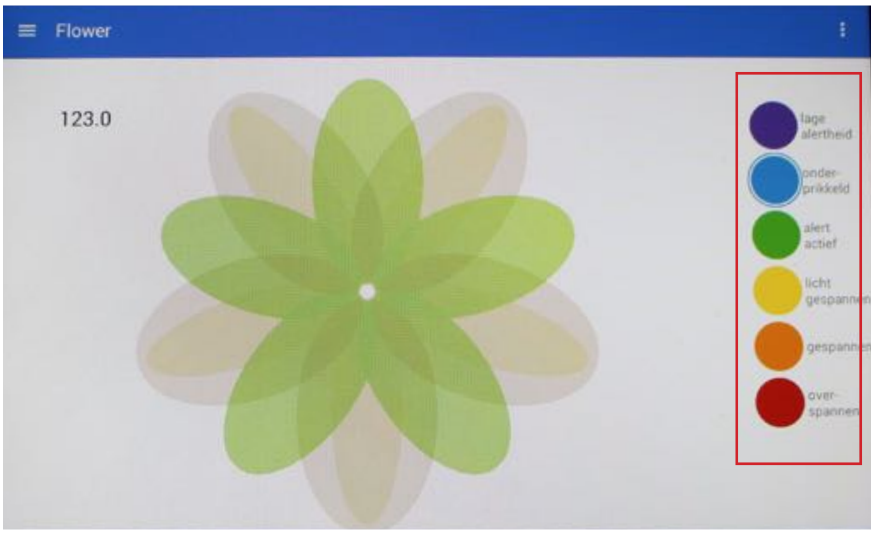
Tijdens het onderzoek zal van u gevraagd worden om uw observaties van het gedrag van uw cliënt in te geven op de tablet. Voor deze observaties kunt u gebruik maken van het persoonlijke signaleringsplan van uw cliënt. In dit signaleringsplan wordt gebruik gemaakt van een kleurcodering. Deze kleurcodering vindt u ook terug op de tablet. Naast de bloem zijn zes gekleurde knoppen (gekleurde cirkels) zichtbaar (17). De kleuren, paars, blauw, groen, geel, oranje, rood, komen overeen met het signaleringsplan. U kunt uw observaties in geven door de gekleurde knop, die hoort bij het gedrag zoals beschreven in het signaleringsplan, aan te tikken. Er verschijnt nu een cirkel om de knop. Deze cirkel geeft aan welke kleur u geselecteerd heeft. Deze knop blijft aan staan totdat u een andere kleur aantikt. Dit houdt in dat als u geen verandering van gedrag waarneemt u niet steeds opnieuw dezelfde knop hoeft in te drukken. Pas als u een verandering in gedrag waarneemt, hoeft u iets te doen, namelijk een nieuwe kleur, die overeenkomt met het nieuwe gedrag, te selecteren.



(15) Groene bloem



(16) Groene bloem met oranje bloemblaadjes



(17) De gekleurde knoppen voor observaties

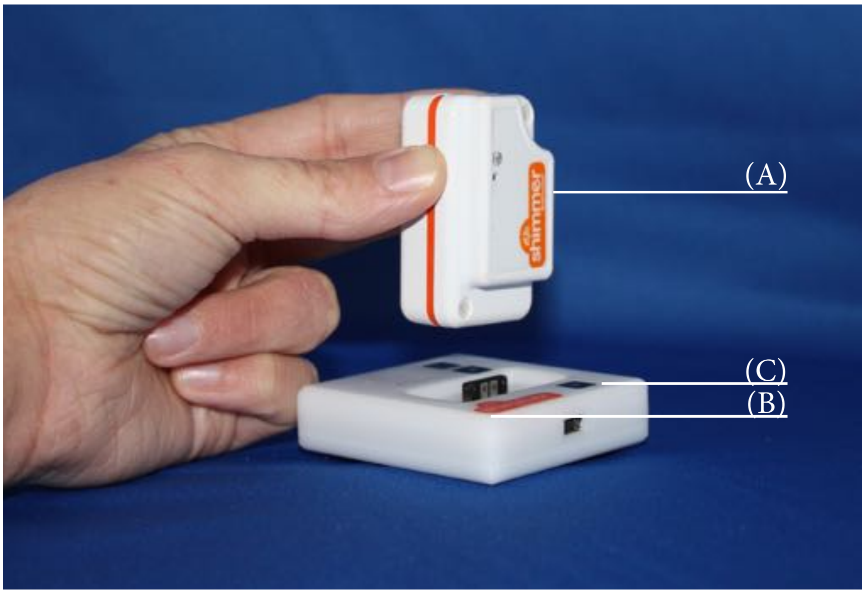
7. HET SYSTEEM AFSLUITEN

DE TABLET AFSLUITEN

U wordt vriendelijk verzocht om de Flower app te stoppen en af te sluiten voor u de tablet uitschakelt! Hoe u de app stopt en afsluit, staat beschreven in hoofdstuk 4.4 op pagina 15. Schakel de tablet uit door de aan/uit knop aan de rechter zijkant van de tablet even in gedrukt te houden. Er verschijnt een menuvenster 'Apparaatopties'. Tik op 'uitschakelen'. Er verschijnt een nieuw menuvenster: 'Uitschakelen'. Tik op 'OK'. De tablet wordt nu afgesloten.

DE SHIMMER MODULE AFSLUITEN

Om de Shimmer module uit te zetten, heeft u de Shimmer module en de Shimmer oplader nodig. De oplader hoeft geen stroom te krijgen. Plaats de Shimmer module met de uitstekende kant (A) naar voren op de oplader, die zo moet staan dat de tekst zich in de linkerhoek (B) bevindt. De Shimmer module kan maar op één manier op de oplader geplaatst worden, dus let goed op of de Shimmer module en de oplader op dezelfde manier staan als in afbeelding 18. Er is geen kracht nodig om de Shimmer module op de oplader te plaatsen, dus forceer dit niet.



(18) Het plaatsen van de Shimmer module op de oplader

Druk op de kleine vierkante knop in de rechterhoek van de oplader (C). Als het lampje in de aan/uit knop (C) uit gaat, staat de Shimmer module uit. De Shimmer module kan nu van de oplader afgehaald worden. Haal de Shimmer module meteen van de oplader af. Als de Shimmer module na 20 seconden nog in de oplader staat, schakelt deze soms automatisch weer aan.

8. HET SYSTEEM OPLADEN

DE TABLET OPLADEN

Sluit de tablet oplader volgens de afbeelding (19) aan op de tablet. Steek de oplader vervolgens in het stopcontact. De tablet wordt nu opgeladen. Het maakt niet uit of de tablet aan of uit staat. Als de tablet wordt aangesloten op stroom laadt deze automatisch op.

TIP: Laad de tablet regelmatig op. Wanneer de batterij van de tablet leeg is, duurt het erg lang voordat deze weer opgeladen en bruikbaar is.

(19) De oplader aansluiten op de tablet

DE SHIMMER MODULE OPLADEN

Om de Shimmer module op te laden, heeft u de Shimmer module en de Shimmer oplader nodig. Plaats de Shimmer module met de uitstekende kant (A) naar voren op de oplader, die zo moet staan dat de tekst zich in de linkerhoek (B) bevindt. De Shimmer module kan maar op één manier op de oplader geplaatst worden, dus let goed op of de Shimmer module en de oplader op dezelfde manier staan als in afbeelding 18. Er is geen kracht nodig om de Shimmer module op de oplader te plaatsen, dus forceer dit niet. Steek de oplader in het stopcontact. Als de Shimmer module wordt opgeladen, brandt het lampje op de oplader (het lampje dat zich het dichts bij de Shimmer module bevindt).

LET OP!!: Wanneer de Shimmer module wordt opgeladen, schakelt deze automatisch aan. Schakel de Shimmer module uit, na het opladen, als u de Shimmer module niet nodig heeft. Op deze manier gaat de batterij langer mee. Op pagina 18 staat beschreven hoe u de Shimmer module uitschakelt.

9. HYGIËNE

WASINSTRUCTIES VOOR DE SOK

1. Draai de sok binnenstebuiten zodat er niets achter de garen, die de drukknoopjes met de stoffen elektrodes verbinden, kan blijven haken.

2. Stop de sok in het waszakje dat u samen met de sok heeft ontvangen, zodat in het uitzonderlijke geval dat de drukknoopjes losraken, deze de wasmachine niet kunnen beschadigen.

3. De sok kan met elk soort wasmiddel gewassen worden.

4. Was de sok op 60°C of op lagere temperaturen.

5. Was de sok niet in combinatie met lichte kleuren, de donkere sok kan kleur afgeven op de andere kleding.

6. Stop de sok niet in de droger.

7. Gebruik de sok niet met de sensor als de sok nog niet helemaal droog is!

SCHOONMAAKINSTRUCTIE VOOR DE SENSOR

De sensor en de band zijn waterbestendig, maar dit betekent niet dat ze onder water gedompeld kunnen worden of onder de kraan schoongemaakt kunnen worden. Reinig de sensor en de band met een vochtige doek en eventueel een klein beetje mild schoonmaakmiddel. Gebruik bij voorkeur alleen een vochtige doek.

Appendix C Arousal & Valence - Coding manual

Behaviour observations – scoring manual

I. Arousal

Arousal is a primitive force that activates behaviour (Pfaff, Ribeiro, Matthews, and Kow, 2008). "An animal or human with a greater degree of generalized CNS arousal (1) shows greater responsiveness to sensory stimuli in all sensory modalities; (2) emits more motor activity; and (3) is more reactive emotionally" (p. 14, Pfaff, Ribeiro, Matthews, and Kow, 2008). We define arousal as the amount of emotion or tension a person experiences (both positive tension of being exited and the negative tension of being stressed or upset). Low arousal is associated with a calm and relaxed state. High arousal is experienced when one is angry or excited.

Count to five after assigning an arousal score to the video. If, after 5 counts, no new events that belong to the current score occur, assign a lower score to the video. If, after 5 counts, new events belonging to the current score do occur, maintain the current score.

1. Very Low: The client is being passive and hardly shows any response to the interaction with the caregiver or to stimuli from the environment. The client is drowsy, asleep or absorbed in his/her own thoughts.
2. Low: The client shows (very) little response to the interaction with the caregiver or to stimuli from the environment, but does express some emotion. The client is discontented/content and moves a little restless regardless whether the motion expressing positive or negative valence. If the client does show responses, the responses are short, the client's attention for the interaction with the caregiver or stimuli from the environment wanes and responses fail to appear when the interaction or the stimulus is repeated.
3. Moderately low: The client is alert and shows a mild expression of emotion (e.g. displeasure or interest). The client shows interest in the interaction or the provided stimuli and shows a response to these stimuli. The client's attention is directed towards the caregiver, however the interaction between the client and the caregiver does not flow back and forth.
4. Moderately high: The client is alert and responsive to the interaction with the caregiver or to stimuli from the environment. The client expresses his/her emotions; e.g. through clapping his/her hands, smiling, pulling his/her hand away from a toy or the caregiver, making whining sounds.
5. High: The client is alert and responsive to the interaction with the caregiver or to stimuli from the environment. The score fits a client who clearly expresses his/her emotions regardless of the nature of the emotion (happiness, sadness, anger, etc.). The client can show this through

for example laughing out loud, crying or screaming. The client expresses non-verbally a strong displeasure or joy.

6. Very high: The client is overstrung and is freaking out. The client has no control over his behaviour. The client may express this through yelling, raging, being aggressive towards the caregiver (kicking, hitting, biting, etc.) or injuring himself/herself (biting, scratching, etc.).

II. Valence

Valence is the value of the emotion or tension. It can be neutral, positive or negative. Negative valence varies from tired, bored, depressed, and miserable to frustrated, stressed, angry, and afraid. Positive valence is ranged from sleepy, calm, relaxed, and content to happy, delighted, excited, and astonished.

Count to five after assigning an arousal score to the video. If, after 5 counts, no new events that belong to the current score occur, assign a lower score to the video. If, after 5 counts, new events belonging to the current score do occur, maintain the current score.

-6. Very high negativity: The client expresses a lot of negative behaviour. The client is raging, ferocious, extremely frustrated, very scared or overstrung. The client has no control over his/her behaviour and is aggressive towards the caregiver. The client is crying out, destroying his/her environment, crying, is inconsolable, shaking beyond control or severely injuring himself/herself.

-5. High negativity: The client clearly expresses negative behaviour. The client is angry, frustrated, scared or stressed. The client shows mild aggressive behaviour towards the caregiver, yells/screams, throws objects away, breaks objects, cries, is shivering, or injuring himself/herself.

-4. Moderately high negativity: The client is severely irritated, frustrated, is upset or slightly stressed. The client refuses to cooperate in activities or rejects interaction with the caregiver. The client walks away from the caregiver, firmly turns his/her back towards the caregiver, or fends off the caregiver (e.g. pushing the caregiver away). The client firmly counteracts and opposes. The client vocalizes protesting, frustrated or angry sounds or verbalizes his/her protest, frustration or anger. The vocalisations are varying in tone and/or in volume.

-3. Moderately low negativity: The client expresses irritation or mild frustration. The client rejects or evades certain activities through pushing or throwing objects away. The client rejects or evades interaction with the caregiver by turning his/her back towards the caregiver or through creating distance between himself/herself and the caregiver. The client counteracts and opposes. The client vocalizes protesting, frustrated or irritated sounds or verbalizes his protest, frustration or irritation. The vocalisations are monotonously and/or low in volume.

-2. Low negativity: The client shows slightly negative behaviour. The client is bored, does not participate/cooperate in activities or evades interaction with the caregiver (for example through pulling his/her hand from the caregiver's hand). The client vocalises or verbalises his/her boredom, dissatisfaction or mild irritation.

-1. Very low negativity: The client shows slightly negative behaviour. The client is slightly bored, disinterested in the interaction with the caregiver or the objects and does not consider the interaction or the objects to be fun.

0. Neutral: The client does not show positive nor negative emotion. The client is passive, unresponsive or deeply asleep.

1. Very low positivity: The client is calm and attentive. The client does not reject the interaction with the caregiver or the activities, but is paying attention or shows a low level of interest.

2. Low positivity: The client is relaxed. The client shows little response to the activities and/or the interaction with the caregiver, but does express interest in the activities and/or interaction with the caregiver. The client makes brief contact with the caregiver through a short touch or vocalising or verbalising monotonously and/or low in volume.

3. Moderately low positivity: The client is content and/or pleased. The client expresses positive emotion through smiling, responding to activities and/or interaction with the caregiver, participate actively and/or request the caregiver's attention. The client connects to the caregiver through clear vocalisations varying in tone, through talking in neutral tones, through being physically close to the caregiver or through touch, for example taking the caregiver's hand. The client initiates interaction with the caregiver, however the interaction between the client en the caregiver does not flow back and forth.

4. Moderately high positivity: The client is joyful, excited or mildly amused. The client expresses this through laughing, clapping his/her hands, vocalising in loud and varying tones or verbalising, imitating the caregiver or seek (physical) closeness to the caregiver. The client reacts positively to activities and the interaction with the caregiver, is active, and takes initiative in establishing activities, connection with the caregiver or interaction. The interaction between the client en the caregiver flows back and forth. The client actively reacts to the caregiver and is both verbally and non-verbally expressive.

5. High positivity: De client is excited, amused and/or happy. The client is laughing elatedly, laughing out loud, beaming or showing enthusiasm (for example through clapping his/her hands). The client reacts very positively to activities and the interaction with the caregiver, is active, and takes initiative in establishing activities, connection with the caregiver or interaction.

6. Very high positivity: The client is excited and/or astonished. The client is roaring with laughter, cannot control his/her enthusiasm, cannot sit still from excitement, shakes his/her hands and/or arms, claps his/her hands fast and loud, and vocalises or verbalises quick and elated.

Appendix D Challenging Behavior - Coding manual

Behaviors relevant to challenging behavior

I. AGGRESSIVE BEHAVIOR

Hitting
The client intentionally hits another person in his environment. It does not concern accidently hitting a person while gesturing or reaching.

Kicking
The client intentionally kicks another person in his environment. It does not concern accidently kicking a person while moving his/her legs.

Pushing
The client places his/her hand(s) on another person in his environment and uses force in an attempt to create distance between himself/herself and this person. This is also scored when the client uses his/her body to push away another person in his environment.

Grabbing/pulling
The client grabs an arm or the hair of another person in his environment and/or pulls at the other's arm or hair.

Scratching
The client intentionally uses his/her fingernails to hurt another person in his environment. This is also scored when the client does not move his fingernails over the other's skin, but instead digs his/her nails into the other's skin.

Pinching
The client pinches another persons in his environment.

Biting
The client bites another persons in his environment.

Spitting
The client spits in the direction of another person in his environment

Damaging objects
The client intentionally damages an object in his environment. This could be through hitting or kicking the object, but also throwing or hitting the object against another object. If an object is damaged by accident, this is not scored here.

Verbally aggressive
The client uses bad language or language that is intended to hurt someone else's feelings.

II. SELF-INJURING BEHAVIOR

Hitting self
The client intentionally hits himself/herself.

Kicking self
The client intentionally kicks himself/herself.

Pulling hair
The client pulls at his/her hair.

Scratching self
The client scratches himself/herself in a way that injures the skin. Scratching because of an itch is not scored here.

Pinching self
The client pinches himself/herself or picks his/her skin or other body parts.

Biting self
The client bites himself/herself. This is not scored when the client has his/her hands or fingers in his/her mouth. Only when the client closes his mouth and bites on his/her hands or arms.

Eye poking
The client presses his/her finger into his eyes. It is not rubbing the eyes because of tiredness or itchiness, but with the intention to cause pain.

Vomiting
The client is gagging or vomiting.

III. STEREOTYPED BEHAVIOR

Rocking
The client is repetitively moving his/her body back and forth or sideways.

Head-rolling
The client repetitively moves his/her head back and forth or sideways.

Pointing
The client has his/her index finger stretch out and is pointing or waving this finger repetitively or for long periods of time without obvious function for this pointing/waving behavior.

Waving
The client has his/her hand lifted and is waving this hand repetitively or for long periods of time without obvious function for this waving behavior.

Teeth grinding
The client is grinding his/her teeth together

Yelling
The client is calling out at the top of his/her voice.

Screaming
The client is calling out with a high-pitched voice.

Note: Count to five after assigning a score to the video. If an event that belongs to the same score, occurs or the same event occurs again, combine both events in one score.

Appendix E Joint Attention - Coding manual

Behaviors relevant to joint attention

I. PRELIMINARY BEHAVIORS (PB)

Find objects
The client uses the caregiver's body to find objects, e.g. tactually scanning the caregiver's body to the hand that may hold an object.

Gestures towards object
The client shows behavior that may be interpreted as gestures concerning objects, e.g. discarding an object after fleeting contact or resists having an object taken away.

Self-stimulating behavior
The client performs self-stimulating behavior that may be interpreted as gestures concerning objects, e.g. the child shakes his head in a back and forth fashion.

II. BASIC JOINT ATTENTION (BJA)

Pointing
The client points in the direction of the object (because of the visual impairment the client may point in the general direction of the object instead of directly to the object).

Focusing attention
The client concentrates on the sounds of the object or the caregiver's voice (e.g. The client stops (un)controlled movements and looks upwards to be able to focus on the sound).

III. ASSOCIATED JOINT ATTENTION (AJA)

Follow direction
The client follows the sounds of the object or the caregiver's voice with head movements (e.g. moving the ear closer to the sound source).

Show object
The client shows the object to the caregiver, e.g. the client moves the caregiver's hand towards an object.

Checking
The client consciously touches the caregiver's hand, arm or leg to check whether the caregiver is still present (reaching for the caregiver's hand, arm or leg is not sufficient for this score) or calls the caregiver's name.

Labels

The client labels an object, an action or an intention through the use of words or signs (e.g. clapping hands to switch on the music).

Take

The client accepts an object from the caregiver (also when the client immediately throws the object away, accepting the object is sufficient for this score).

Give

The client offers an object to the caregiver. The client holds the object until the caregiver reaches for or takes the object from the client.

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Curriculum Vitae

Kyra Frederiks received her Bachelor's (2012) and Master's degree (2014) in Industrial Design at the Eindhoven University of Technology. During her study, she was involved in several projects that aimed at supporting the bonding and/or communication process between parents and children (with disabilities). In June 2015, Kyra started as a PhD student in a collaboration project between the Eindhoven University of Technology and the Vrije Universiteit Amsterdam. In this project she is developing and evaluating a bioresponse system to support the interaction process between individuals with visual and severe or profound intellectual disabilities and their caregivers.

Publications

2021

Frederiks, K., Sterkenburg, P., Barakova, E. & Feijs, L. (under review). A Bioresponse system for professional caregivers of adults with visual and severe/profound intellectual disabilities: the effects on sensitive responsiveness and challenging behaviour. *Journal of Intellectual & Developmental Disabilities*

2019

Frederiks, K., Sterkenburg, P., Barakova, E. & Feijs, L. (2019). The effects of a bioresponse system on the joint attention behaviour of adults with visual and severe or profound intellectual disabilities and their affective mutuality with their caregivers. *Journal of Applied Research in Intellectual Disability*, 1–11

Frederiks, K., Sterkenburg, S., Lavner, Y., Cohen, R., Ruinskiy, D., Verbeke, W. & IJzerman, H. (under review). Mobile Social Physiology as the Future of Relationship Research and Therapy: Presentation of the Bio-App for Bonding (BAB).

2017

Sterkenburg, P., Frederiks, K., Barakova, E., Chen, W., Peters, P. & Feijs, L. (2017). A bioresponse system for caregivers of adults with severe or profound Intellectual disabilities. *Journal of Mental Health Research in Intellectual Disabilities, 10*(Suppl. 1), 121-121.

2015

Frederiks, K., Croes, M., Chen, W., Bambang Oetomo, S., & Sterkenburg, S. (2015). Sense – a biofeedback system to support the interaction between parents and their child with the Prader-

Willi syndrome: A pilot study. *Journal of Ambient Intelligence and Smart Environments, 7*(4), 449-459.

2014

Frederiks, K., Croes, M. (2014). Biofeedback System For Parents And Children With Prader-Willi Syndrome. *ACM CHI Conference on Human Factors in Computing Systems 2014.*

Magazine articles/ Newsletters

2018

Newsletter. Onderzoek 'het effect van het biorespons systeem voor begeleiders van volwassenen met een visuele- en (zeer) ernstig verstandelijke beperking. *Visio Nieuwsflits* (September editie)

2017

Newsletter. Onderzoek 'het effect van het biorespons systeem voor begeleiders van volwassenen met een visuele- en (zeer) ernstig verstandelijke beperking. *Visio Nieuwsflits* (April editie)

2015

Magazine article. Gijzen, T. (2015). Slimme sok pikt signalen cliënt op. Klik, 5, 12 – 14

Newsletter. Slimme sok pikt signalen passieve cliënten op. *Bartiméus B-Connect* (July, 2nd)

(Poster) Presentations:

2021

Presentation "Het gebruik van de slimme sok in de praktijk". *Presentation for the staff of the department Expertise centrum Doofblindheid* (Online, June 17th)

Workshop "Technology in Practice – The Bioresponse system". *Minor Measurement, Analysis, Design & Exploration for Allied Healthcare, Fontys hogeschool, Eindhoven*. (Eindhoven, the Netherlands, April 19th)

Presentation "Het gebruik van de slimme sok in de praktijk". *Refereeravond: Wearables in de zorg, een zorg meer of minder?* (Online, March 25th)

Presentation "Het Bioresponse systeem – het gebruik van de slimme sok bij mensen met een ernstige meervoudige beperking". *2e kennisdeel bijeenkomst zorgkantoorregio's Zwolle en Apeldoorn/ Zutphen (Thema: Monitoren/ voorkomen van stress bij cliënten)*. (Online, March 18th)

2020

Presentation. Theoretische achtergrond. *Codeertraining Aansluiten & Stimuleren Checklist.* (Amsterdam, the Netherlands, January, 6th).

Presentation. Het effect van het Bioresponse systeem op de interactie tussen begeleiders en cliënten met EMB. *Presentation for the staff of the department 'Psychotherapie' at Bartiméus.* (Online, November, 3th).

Lecture. Gehechtheid, gedeelde aandacht en ICT. *Course "Technologie en Media in Opvoeding en Onderwijs. Bachelor Pedagogische en Onderwijswetenschappen"* (Online, November, 4th).

2019

Presentation. Arousal & De 'Slimme sok'. *Masterclass Pijnsignalering: mensen met ernstige verstandelijke beperking* (Amersfoort, the Netherlands, January, 22nd).

Presentation. Gebruik van fysiologische maten (de 'slimme sok') in de dagelijkse praktijk. *Congres Kennisinfrastructuur Langdurige Zorg* (Nieuwegein, the Netherlands, January, 31st).

Presentation. The 'Smart Sock' as a mediator. *Masterclass ICT as a mediator in the healthcare of people with a visual and/or intellectual disability* (Amsterdam, the Netherlands, April, 17th).

2018

Presentation. De slimme sok. *Wereldcafé Bartiméus* (Zeist, the Netherlands, February, 5th).

Pitch. The Bioresponse system. *Pitch your Project for members of the Research Group Future Everyday, Industrial Design faculty* (Eindhoven, the Netherlands, February, 28th).

Presentation. The effects of the Bioresponse system for adults with visual and severe/profound intellectual disabilities. *Presentation for members of the Département de Pédagogie curative et spécialisée, Université de Fribourg* (Fribourg, Switzerland, June, 1st).

Poster. Joint Attention bij mensen met een visuele- en (zeer) ernstig verstandelijke beperking: het effect van het gebruik van de slimme sok. *Congres Focus op Kennis voor gehandicaptenzorg* (Ede, the Netherlands, June, 1st).

Presentation. Het effect van het Bioresponse system voor begeleider van volwassenen met visuele- en (zeer) ernstig verstandelijke beperking. *Presentation for the staff of the department 'Psychotherapie' at Bartiméus* (Doorn, the Netherlands, June, 7th).

Poster. Het bioresponse system – de slimme sok en app. *JIJ & IK Festival, Ons Tweede Thuis* (Amstelveen, the Netherlands, June, 8th, 9th & 10th).

Presentation. Het effect van het Bioresponse system voor begeleider van volwassenen met visuele- en (zeer) ernstig verstandelijke beperking. *Kennisdag Bartiméus, Koninklijke Visio en Robert Coppes Stichting* (Zeist, the Netherlands, June, 14th).

2017

Presentation. A Bioresponse system - to support the communication process of individuals with severe/profound intellectual disabilities. *Presentation for members of Research Group Designed Intelligence, Industrial Design faculty* (Eindhoven, the Netherlands, March, 23rd, May, 4th, June, 1st).

Poster. The effects of a Bioresponse system on the interaction between individuals with severe/profound intellectual disabilities and their caregivers. *ISED PhD Days Leuven* (Leuven, Belgium, June, 7th).

Presentation. A Bioresponse system - to support the communication process of individuals with severe/profound intellectual disabilities. *DondersDiscussion* (Nijmegen, the Netherlands, October, 26th)

2016

Presentation. Pilot Test Results - Measuring pain with the Bioresponse sensor sock. *Participants and staff involved with participants of Esdégé-Reigersdaal* (Heerhugowaard, the Netherlands, February, 18th).

Presentation. Pilot Test Results – Bioresponse System. *Participants and staff involved with participants of Bartiméus* (Doorn, the Netherlands, April, 28th).

Presentation. A Bioresponse system - to support the communication process of individuals with severe/profound intellectual disabilities. *Presentation for members of Research Group Designed Intelligence, Industrial Design faculty* (Eindhoven, the Netherlands, May, 26th, June, 9th & 23rd, October, 20th, December, 15th).

2015

Presentation. Intelligent systeem om de communicatie tussen ouders en hun jonge kindje met Prader-Willi Syndroom te ondersteunen. *Congres Focus op Kennis voor gehandicaptenzorg* (Utrecht, the Netherlands, June, 22nd).

Poster presentation. Design to support people with communication impairments. *Domoticabeurs* (Eindhoven, the Netherlands, November, 18th & 19th).

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