Give the Body a Voice: Co-design with Profound Intellectual and Multiple Disabilities to Create Multisensory Wearables

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ABSTRACT

This study explores non-verbal co-design techniques with multisensory wearables to give the body a voice. Sessions were led with professional caregivers, parents, and clients with PIMD (profound intellectual and multiple disabilities) to find fundamental building blocks for a common language based on tangible technologies. To provide an agent for communication we employed the tools of extimacy - translating biodata to visual, auditory, or tactile interactive displays. The caregivers expressed the need for action – reaction "Actie Reactie" to keep attention, which was an update from the Multisensory Environment (MSE) rooms previously used to calm. In the co-design sessions, we found the on-the-body wearables held the most focus. The final discovery from the study became the outline for creating a modular, highly personalized kit for a Multisensory Wearable (MSW) to inspire surprise and wonder.

CCS CONCEPTS

• **Human-centered computing** → **Participatory design**; *Haptic devices*; • **Social and professional topics** → **People with disabilities**; • **Computer systems organization** → *Sensors and actuators.*

KEYWORDS

multisensory; wearable; PIMD; non-verbal; co-design; biosensing; extimacy

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1 INTRODUCTION

In the Netherlands, about 10,000 people have Profound Intellectual and Multiple (physical) Disabilities (PIMD) [1]. They have a developmental age of a 2-year old child or younger, and one or more physical disabilities such as cerebral visual impairment or hearing impairments. Due to the combination of intellectual and physical disabilities, people with PIMD need intensive individualized care and support. One of the biggest challenges is communication: people with PIMD often have underdeveloped language ability and are not able to express themselves through spoken language, and they often have difficulty in maintaining their awareness of environmental events. As such, their ways of communication are often idiosyncratic and if present at all, consists of vocalizations or short words, eye movements, and subtle gestures. Caregivers are continuously alert for these few communicative signals and learn to read the person's cues. As a way to stimulate and elicit positive reactions and interactions between persons with PIMD and their environment (and sometimes for therapeutic purposes), Multisensory Environments (MSE), equipped with objects that stimulate multiple senses, are often used [3, 10].

In contrast with previous work, we focus on multisensory wearables (MSW) for PIMD. We report on our studies in non-verbal sensory co-design to stimulate multiple senses with (wearable) sensor and actuation technology. This was done through a co-design process in which we involved clients with PIMD, their parents, and their professional caregivers. The parents and professional caregivers interpreted the reactions of the clients as communication and understanding is impaired for them. One of our aims was to investigate how multisensory wearables, in particular biofeedback, can elicit positive behavior from clients with PIMD and give the non-verbal clientele a voice. We explored extimacy - expressive biofeedback that translates internal feelings to external visual, auditory, or tactile displays. After initial co-design sessions, a 6-week long study with next iteration of designs was carried out to investigate the reactions of the clients and caregivers in more depth with repeated use. We report on initial results in researching and designing extimacy with multisensory technology for and with people with PIMD.

2 RELATED WORK

A multisensory environment (MSE) can be defined as a space equipped with sensory materials that provide users with (mostly) visual, auditory, tactile, and olfactory stimulation, usually with the aim of offering stimulating or relaxing experiences to individuals with cognitive and behavioural impairments, including people with very severe intellectual (and physical) disabilities [3, 10]. First created in the Netherlands, MSEs are also represented by the Dutch verb "snoezelen" [13], a contraction between "sniffing" and "dozing" referring to the processes of multisensory exploration and relaxation. "Snoezelen" is characterized by its "non-directive use", lacking specific educational or therapeutic aims, imposed by the ones facilitating it [7, 13] and rather focusing on relaxation, enjoyment and facilitation of interpersonal relationships as outcomes. Meta-analyses have shown indeed, that in general, "snoezelen" has

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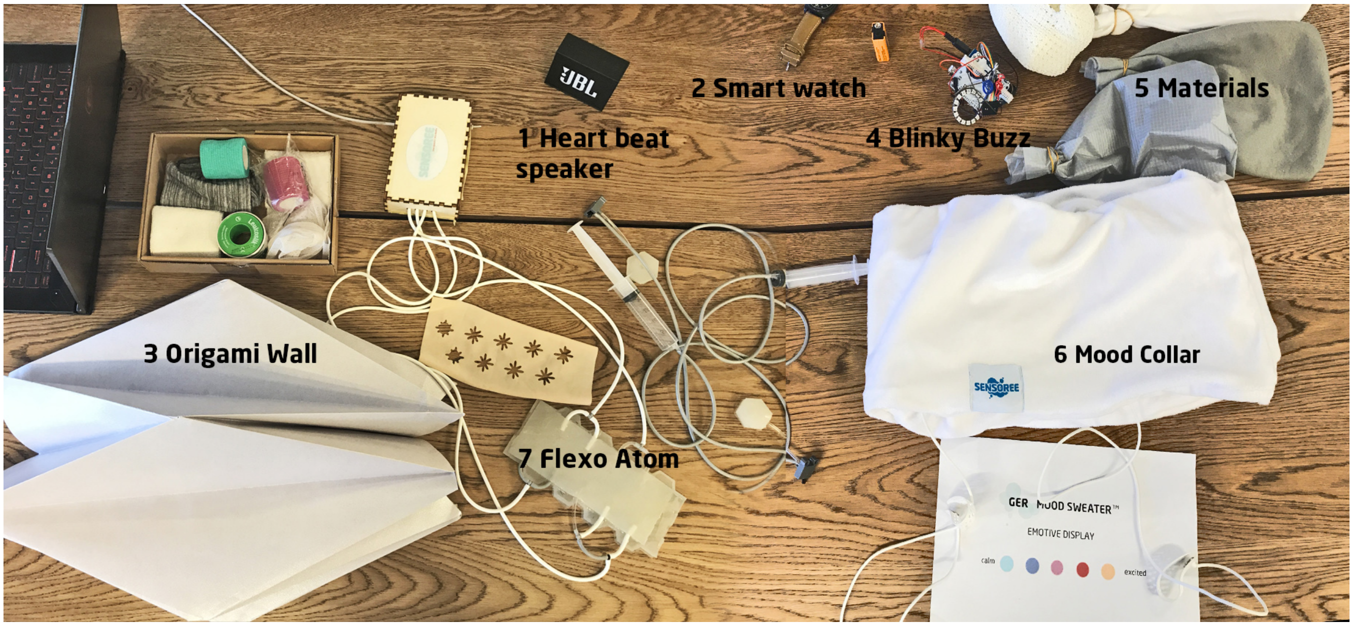

Figure 1: Design probes used in the co-design sessions.

positive outcomes for people with PIMD [7] that seems to even extend to therapeutic use [8]. However, these analyses also stress individual differences [14] and that "snoezelen" is not a cure-all for everyone [7].

MSEs are typically equipped with aromatherapy, music, adjustable lighting, a projector, a rocking chair, bean bags and weighted blankets ([3]). However, many of these devices are limited in their interaction behaviors and the range of reactions they can elicit. More recently, designers come up with more versatile multisensory devices that react to gross body movements, focus of attention and vocalizations (interactive ball [12]), or touch, sounds, and hugging (SID project [2]), or even biosignals (StimuHat [5]; sensor in sock with a flower app [4]), while generating visual, auditory or tactile feedback. A few of these designs are also wearable ([4, 5]).

In our current studies, we particularly focus on multisensory on-the-body wearables (MSW) while looking for positive responses from the clients elicited by our bioresponsive artifacts. Positive responses include signs of enjoyment, relaxation, curiosity, or alertness.

3 CO-DESIGN SESSIONS

First, co-design sessions were held with the professional caregivers, the clients' parents, and the clients themselves (with caregivers present). These sessions took the form of interviews, brainstorms, and hands-on interactions. Several design probes were presented in these sessions and evaluated. The goals of these sessions were to get an impression of what kind of multisensory sensing and stimulation would be suitable for the clients, and to gather people's ideas about multisensory stimulation via design probes. These sessions took place at one of the locations of De Parabool (location De Schure in Deventer, NL), a care facility for persons with PIMD. These co-design sessions were approved by the EWI Ethics Committee from the University of Twente (RP 2019-93).

3.1 Co-design with professional caregivers

Five professional caregivers participated in this brainstorm session. The caregivers were asked about the clients' preferences for materials, toys, and what kind of multisensory stimulation they currently used that worked well. The caregivers mentioned that music, noises, light effects, and anything with clear contrast and clear changes (like blinking) works with their clients. Some clients have Epilepsy, but a seizure has not been triggered with blinking lights. They were interested in having projections on the wall or floor that can be adjusted to each client's preference and personality as each client is different. There were some collective takeaways with sensory input. Hearing was the most pronounced sense. Although sight was most limited, there was a preference for aquatic themes visually and kinetically how water and fish moved. Finally, how physical presence and touch was a powerful tool to calm.

For bio-sensing, we presented sensors on the hand, finger or wrist. This could be problematic for some of the clients as some have fused fingers or do not like things attached to their hands, so the caregivers suggested to try a smartwatch on the wrist. They would like a MSE, but in the current Snoezelen rooms the clients tend to disassociate. The caregivers express a desire for an updated design, so the clients get more stimulation of the senses. The interaction that we design should be simple and clear, action – reaction, *Actie Reactie* and hold the attention of the client. Finally, the designs should be durable as some of the clients can break or throw things. Also, modular to be used in other spaces or even taken home for a few weeks.

(a) Client wearing the Mood Collar (b) One of the clients and caregiver testing Flexo and the Mood Collar (c) One of the clients testing Blinky Buzz with Mood Collar

Figure 2: Clients testing the artifacts.

3.2 Co-design with clients' parents

The parents of 4 clients (2f, 2m, 18-35yr: C3, C4, C5, C6) participated in this interview session. The same questions that were asked to the professional caregivers were asked of the parents. In addition to the biosensors on the hand, finger or wrist, we brought different kinds of materials (laser cut fabric, 3d print fabric), an origami cover, an inflatable pocket to be placed under the palm of the hand, and an arduino-based sounding and blinking toy (see Fig. 1). With respect to the materials, each client has different and specific preferences for materials as expected. For example, C5's mother explains that C5 does not like plastic or metal, but she does like wood. C5 does not like human touch, that is why her mother thinks the inflatable is a good idea. Other parents showed interest in the inflatable as well: C3's mother thinks that C3 will like the inflatable as it also vibrates, C6's dad thinks that the inflatable might help C6 to calm down after a seizure. When talking about the placement of the inflatable, C4's mother mentions that C4 likes wearing things on his forehead. Similar to the professional caregivers, parents also mentioned projections kept attention, and calm down time. They also thought that using a heartbeat sound or white noise in one of the designs could have a soothing and calming effect. Finally, none of parents had thought of biosensing for monitoring, as a communication tool, or as input for stimulation. C6's father did note he unconsciously interprets his son's biosignals - he can tell if a seizure is coming by the sound of his breath, increased temperature, and the sound of knocking around in the bed. The only thing that calms C6 down during a seizure is touch. All parents would like to be involved and informed, and see the development which is very positive.

3.3 Co-design with clients

We carried out one-on-one sessions with 4 clients (2f, 2m, 18-35yr: C1, C2, C3, C4) who tried several design probes, the professional caregivers were always present. Consent to participate in these sessions was given by the clients' parents. Based on the input from the professional caregivers and the clients' parents, we iterated on the preliminary designs and decided to test the following probes (see Fig. 1):

1 Heartbeat sounds on speaker The parents mentioned sound was the strongest sense. We combined the idea that heart rates synchronize with each other.
2 Smart watch on the wrist The caregivers thought this could be an alternative for a hand sensor.
3 Origami folding wall A lo-fi prototype to define personal space with changeable wall. Both professional caregivers and the parents mentioned the need for alone time. This could create a small, private room.
4 Blinky Buzz A movement-based light and vibration feedback toy to encourage interaction. Caregivers suggested client like blinky lights and vibration.
5 Four materials to touch Cotton, wool, ripstop, 3d print fabric as each client has different preferences.
6 Mood Collar The Mood Collar[1] is a galvanic skin response (GSR) sensor in the palm of the hand that translates excitement levels to a scale of five colors in an illuminated collar, see Fig. 2. Many caregivers noted watching biosignals to monitor clients, but had not yet tried biosensing technology.
7 Flexo Atom An inflatable silicone robot with 9 inflatable pockets that mimic the pressure of a finger. Caregivers and parents liked the idea of remote touch and the sound of the motors.

The probes were tested with the clients one at a time. The caregivers were present to help interpret the clients' reactions. All liked wearing the Mood Collar (MC). It seems comfortable and especially the females got excited to wear it. The sensors were hard to put on hands with poor dexterity and flexibility, but then seem comfortable once on. The Mood Collar was also worn during the testing of the other probes, and showed the clients' excitement levels through the colors. This also helped to show that clients reacted differently to the probes. The caregivers helped pair the colors with the non-verbal cues they knew from the client, that we would miss. For example with C2, "Look at the rapid eye movement, the client is very excited about the Flexo. You can tell by how fast their eyes are moving." With the body language translation of the caregivers, we could then confirm if the excited color was correct.

[1] http://sensoree.com/artifacts/ger-mood-sweater/

Although not interactive, the heartbeat speaker seemed positive for all. The materials were in general liked by the clients, but each had a different preference. The 3d print material seemed to keep attention longer and also the ripstop with the crinkle sound it made. Flexo was popular as many clients liked it, except C1 who was afraid of the silicone. C3 wanted to wear Flexo on their body, specifically their arm and was smiling and laughing "arm arm". C4 put it on their head and was laughing; his mother was correct he would like it on his head. The shaking LED vibration toy was liked by some, but needed the caregiver to shake it. The smart watch had mixed results, especially the females did not like wearing the watch on their wrists. Finally, the origami folding wall was not popular. It was tried on the edge of wheel chairs and on the body. It seemed to obstruct vision and the clients wanted to be involved in the events in the room. They were very curious and aware of the testing and ready for their turn to try.

3.4 Discussion

From the co-design sessions with the professional caregivers, the clients' parents, and the clients themselves, we learned a lot about how to design multisensory stimulation for PIMD. We highlight some of these insights here. First, the involvement and positivism of the professional caregivers and the parents is crucial. The caregivers were very cooperative and enthusiastic, as well as the parents who expressed a willingness to be involved and wanted to see the development. They are indispensable as they are the ones who understand their clients and children the best. Second, as each client is different, the design should preferably be easily adjustable to the client's preferences which implies a modular design. For example, the preference for a stimulating material (e.g., wood, plastic) is very personal, as well as the location to which the stimulation is applied (e.g., C4 likes the forehead). The designs should also be rather durable as some clients' hand dexterity is poor and some can throw things. Third, the interaction is preferably a simple one: an action-reaction sequence that should be stimulating enough that holds the attention of the client, but not too stimulating as the goal is to relax and not to upset the client. This is a fine balance between calm and stimulating that needs to be optimized.

The insights gained from the co-design sessions were used in our six-week follow-up study where we updated the designs and gave to the caregivers to continue to use with the clients. The aim was to see in more detail how the multisensory objects would be used and experienced by the caregivers and clients over a longer period of time. Perhaps new design ideas would evolve. A kit was created, to leave behind for a long-term study at location De Schure. Two Mood Collars one for caregiver and one for client. The Flexo Atom which was redesigned with feedback from the co-design sessions to mimic the size of two hands. The velocity range of 0 to 127 was divided into lower and higher ranges providing low (1.6 N) and high (2.4 N) forces measured by a force sensing resistor (FSR). A syncopated inflation pattern was created to surprise (see Fig. 3). Also, the Blinky Buzz movement reactive toy covered with most popular 3d print fabric. An attempt to make sound reactive was tried, but it was found to react to every sound in the room, not only the clients, and would constantly be triggered. An apron was then created with multiple pockets to hold the Flexo and Blinky Buzz as we wanted to explore stimulation on different body parts. From the co-design sessions, these designs seemed most popular and were ready for long-term testing: they are working out of the box and are relatively durable. Moreover, the Mood Collar was the only design that works autonomously with action-reaction.

Figure 3: Flexo Atom co-designed to be like abstract hands with 9 inflatable finger like pockets.

4 SIX-WEEK CAREGIVER STUDY

The goal of this six-week study was to see in more detail how the Mood Collar, Flexo Atom, and Blinky Buzz would be used and experienced by the caregivers and clients over a longer period of time. This six-week long study was approved by the EWI Ethics Committee from the University of Twente (RP 2019-92).

4.1 Procedure and materials

The caregivers from location De Schure were instructed to use the probes with their clients several times a week. After each experience, the caregivers were asked to fill out a form about the reactions and emotions of the client while using the designs, and to write down any other relevant observations related to the clients' reactions and emotions. Any feedback about the designs (e.g., about its use or potential improvements) were also written down on the forms. The artifacts could be used at any time. Sometimes, the Mood Collar was worn by the client while testing Flexo Atom. For Flexo Atom, we instructed the caregivers to ask the clients to put their hands on the design, and to try on other parts of the body, for example the belly or a leg. An apron with many pockets was provided to help hold the flexo or Blinky Buzz in one location on the body and make wearable. Scissors and fabric was also provided if they wished to add more pockets or different location or affix tighter.

4.2 Participants

In total, 10 participants (5f, 5m) tested the designs. Their ages ranged from 18 to 35. The participants all had an intellectual impairment, and most of the time, other disabilities as well. They were clients from De Schure (one of the locations of De Parabool) and they came there for daytime activities. Many of the clients' skills were limited and unable to talk. Stimuli that could activate the clients must come naturally or be caused by a very small reaction.

4.3 Measurements

The measurements were qualitative of nature and consisted of the caregivers' observations and feedback written down in the forms we provided.

4.4 Results

4.4.1 Clients' experiences. Six clients tried the Mood Collar. In general, the clients enjoyed wearing it. C2 knows how to put on the Mood Collar and the sensors herself - she enjoyed walking around in it. C3 giggled while wearing it. Both clients (C2, C3) seemed to be excited. C7 seems to be more calm while wearing it. For two clients C6 and C4, it was not possible to put on the hand sensors: C6 is very peculiar about holding things in his hands and did not want to put the hand sensors on, while C4 was not able to wear the hand sensors due to fused fingers. Although clients enjoyed the Mood Collar in the beginning, after a while of use, they lost interest in it, and forgot it was there.

Eight clients tried Flexo Atom. C3 was not scared to try Flexo Atom, was curious, laughed a lot and was relaxed while she put her hand on it. C7 has used it several times, was excited about and kept her hand(s) on it. C7 used it often by herself and looked happy, sat relaxed in her chair. Flexo Atom was also tried at different parts of the body such as the upper leg (C8, C7) and belly (C4). C8 sat in a wheelchair and tried it on his upper leg - he smiled and when the caregivers asked him if he liked it, he answered yes by touching the caregiver's hand. C4 tried Flexo Atom on his belly and seemed more relaxed after a while using it. There were also times when the caregivers think that clients (e.g., C7, C6, C1) do not really know what to with Flexo Atom. Moreover, some clients quickly lose their interest and attention, i.e., C1 and C9; the design does not stimulate these clients enough, the interaction should be more challenging and active. In general, all clients enjoyed Flexo – the tactile inflation in combination with the sound and vibration of the motors. Although the sound is not specifically designed for stimulation purposes, it was a byproduct of the motors and created a personality. The multisensory behaviors seemed to create curiosity and a sense of wonder.

4.4.2 Caregivers' feedback. From the caregivers' notes, we found that they sometimes had difficulty interpreting the colors of the Mood Collar. They reported using it to monitor an aggravated client, but then were also unsure when else to use it. The hand sensor design could be simplified to a sticker as hand shapes differed. For Flexo, the caregivers suggested to make the stimulation a stronger actuation. They thought that sometimes it was not felt. They suggested to try a different form of Flexo that can be adjusted to the current shape of one hand. Or try to make a larger surface like a blanket, such that larger parts of the body can be stimulated. The caregivers also suggested to add sounds and colors to enrich the experience. All professional caregivers indicated that they would use the designs more often, especially if "it could do more." Although the Blinky Buzz with 3d print fabric was popular in the initial co-design sessions, it lost interest after multiple uses. Clients tried to throw it and break it. The 3D print was reported to be too stiff and the caregivers requested a softer textile to be nicer to the skin.

4.5 Discussion

In general, in the six-week longitudinal study period where the clients and caregivers used the Mood Collar, Flexo Atom, and Blink Buzz, we mainly learned that the "actie-reactie" action-reaction interaction could be more specific and artifacts could be combined to increase effects. Next steps would be to make the behaviors more explicit as clients sometimes did not know when something reacts, and they sometimes did not really know what else to do with the design, therefore lost attention. There is a design opportunity to combine the artifacts to be multi-modal to keep focus longer with elements of surprise [9]. Although we gave an instruction manual for the Mood Collar, maybe it was not intuitive enough as they were not able to differentiate the demo mode from the working mode when it was on. It should also be mentioned that all clients enjoyed Flexo Atom. It was noted that the Blinky Buzz, perhaps as it was off the body or had too frequent reaction, incited aggressive behavior to throw and break. Finally, we also learned that it is worthwhile to further investigate preferences for specific parts of the body that can be stimulated and that can differ for each client. The caregivers noted stronger, more pronounced interactions would help keep attention and the combination of different modalities, e.g., sound, vibration, and visuals. Also, the on the body designs seem to create insight, somatic integration, and an emotionally durable bond, while off the body instigated play and throwing.

The final outcome of the studies found ingredients to create a MSW for Actie Reactie with calm yet stimulating artifacts with extimacy - biosensing for personalization of visuals, sound, and touch. This is an upgrade from the MSE, which is a room that calms, to an MSW - on the body wearable for extimacy - enhanced body awareness and communication.

5 DISCUSSION AND CONCLUSION

We conclude with the most important lessons learned, and recommendations for future research. Acknowledging recent research in participatory design with communicative or cognitive impaired persons [6, 15], we also stress that involvement of the family and professional caregivers in addition to the PIMD him/herself was indispensable, especially when the main subject did not have a clear voice of his/her own. We found that the adaptive technology of extimacy in MSWs assisted communication by giving the body a voice. Second, this study confirmed the need for highly personalized design. Each client was so unique in how they responded to sensory stimuli, it was not possible to create one universal artifact. A modular kit began to take form, with each of these components could be added or subtracted per person with sensory preference. The bioresponsive component seemed to add a level of personalization that could assist caregivers in the form of adaptive technology to add a new level to the MSE of being able to monitor wellbeing with the displays. Third, we learned that the MSW action-reaction sequence, Actie-Reactie in Dutch, should ideally relax the client, while keeping them engaged. This interaction should be clear and predictable, yet surprising enough to hold the attention of the client. The stimulation should be strong, but not too strong as it might upset clients. The designs need to be sturdy, modular, and adjustable as each client has different preferences and personalities. Fourth, we found that Flexo Atom was most liked by the clients and most promising to further develop it (among the designs we tested) for several reasons. It combines several nonverbal modalities leading to an enriched experience: sounds (although not purposefully intended - the sounds come from the vibration motors), and haptics. Also, Flexo could be used on different parts of the body which also opened up new experience and design opportunities as clients expressed different preferences. Flexo could be further extended in future research as explained below.

For future research, we suggest further explorations on how this adaptive technology could assist caregivers. Also, to address the need for personalisation by continuing to build a modular kit. Finally, to investigate further how to integrate biosensing in the action-reaction sequence. Biosensing has been unconsciously applied by some of the parents and offers the highly personalized interaction for MSE. As projections were often mentioned by the caregivers and parents, this seems an opportunity. Finally, heartbeat sounds from a speaker in general seemed to be liked by many clients, and as it has been shown to have calming effects in other domains [11, 16], it is worthwhile to explore this with PIMD. In conclusion, we learned many lessons and have recommendations for future research to offer the body a voice with sensory technology. The multisensory design focus on this niche group provides valuable insights that may be applied to the larger population to instill curiosity, decrease stress, and increase wellbeing.

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