

RESEARCH ARTICLE

Biomusic: A Novel Technology for Revealing the Personhood of People with Profound Multiple Disabilities

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Abstract

It is often difficult for family members and caregivers to interact with persons with profound multiple disabilities (PMD) because of the severely compromised communicative repertoire of this population. The resulting communication challenges may limit the ability of others to perceive personhood in individuals with PMD. This preliminary study investigated the effects of music generated in real time from physiological signals (*biomusic*) on caregiver perceptions of their interactions with persons with PMD. Caregivers ($n = 10$; parents and clinical staff) engaged in four, 10-min interactions with a person with PMD ($n = 3$; diagnoses = traumatic brain injury, pervasive developmental disorder, hypoxic brain injury), whose biomusic was projected throughout. Caregivers participated in two open-ended, semi-structured interviews to explore the effect of biomusic on these interactions. Most caregiver responses to biomusic were very positive, and many reported that biomusic caused an improvement in their interaction with and perceptions of the person with PMD. By providing audible evidence of the changing physiological state of persons with PMD, biomusic may enhance the perceived personhood of these individuals and enrich interactions with their family members and caregivers.

Keywords: *Communicative interaction; Complex continuing care; Biomusic; Personhood*

Introduction

A growing number of people live with disabilities of such severity that their ongoing survival depends on medical technologies together with skilled professional and/or lay caregivers (Rosenbaum, 2008). The increased prevalence of these individuals has been attributed to improved survival rates of premature infants (Msall & Tremont, 2002) and those born with life-threatening congenital anomalies (Tennant, Pearce, Bythell, & Rankin, 2010; Wong & Paulozzi, 2001), as well as improved treatments for severe illnesses and trauma (Hallahan et al., 2000). Although the etiology of the resulting impairments varies extensively, surviving individuals are behaviorally unresponsive, that is, they are unable to move or speak, and those who care for them report that these persons do not appear to manifest thoughts or feelings in ways that can be reliably interpreted. As a result, it is very difficult to assess the tremendously variable cognitive abilities of these individuals. Some are cognitively indistinguishable from age-matched, nondisabled individuals

(Laureys et al., 2005), while others have severe cognitive and intellectual disabilities ($IQ < 20$) and have been described using such terms as “profound and multiple learning disabilities” (PMLD) (Bellamy, Croot, Bush, Berry, & Smith, 2010) and “profound intellectual and multiple disabilities” (PIMD) (Nakken & Vlaskamp, 2007).

Individuals with PMLD and PIMD have little or no understanding of verbal language and symbolic interactions or capacity for self-support (Goldbart, 1994; Hogg & Sebba, 1986). Furthermore, many have sensory impairments, and especially cerebral visual impairments (Evenhuis, Theunissen, Denkers, Verschuure, & Kemme, 2001; Janicki & Dalton, 1998). Regardless of their level of cognitive functioning, the severely compromised physical repertoire of these individuals renders many unable to engage in intentional communicative interaction. Throughout this paper, we will refer to this collective group of individuals as persons with profound multiple disabilities (PMD). Persons with PMD may

have the ability to engage in pre-intentional behaviors that are meaningful to and interpretable by others (i.e., facial expressions, physical movements or postures, sounds, or muscle tension (Maes, Lambrechts, Hostyn, & Petry, 2007)). However, when viewed within the perspective of frameworks for expressive communication, such as the seven-level Communication Matrix, these behaviors alone are not sufficiently complex to be considered intentionally communicative (Rowland & Fried-Oken, 2010) and function only as communication when interpreted as such by others. Individuals limited to such behaviors are considered *perlocutionary* or *illocutionary* communicators (Ogletree, Bruce, Finch, Fahey, & McLean, 2010); that is, their needs, wishes, and preferences are difficult to interpret and at significant risk of being misunderstood (Grove, Bunning, Porter, & Olson, 1999; Hogg, Reeves, Roberts, & Mudford, 2001).

Although many types of low- and high-tech augmentative and alternative communication (AAC) devices have been developed to facilitate communication with those who have limited ability to move and speak (Ashraf et al., 2002; Costello, 2000; Fager, Beukelman, Karantounis, & Jakobs, 2006; Happ, 2001; Hashimoto, Ushiba, Kimura, Liu, & Tomita, 2010; Neuper, Muller, Kubler, Birbaumer, & Pfurtscheller, 2003; Sellers, Vaughan, & Wolpaw, 2010; Soderholm, Meinander, & Alaranta, 2001), many persons with PMD lack the necessary mental alertness, cognitive or physical functioning, and energy and/or attention to use them (Happ, 2000). Thus, these persons cannot reliably interact or communicate with others, two factors considered essential to adequate quality of life (Hewett & Nind, 1998).

This paper is concerned with enhancing the quality of life of persons with PMD by revealing signs of their personhood. According to Kitwood (1997), personhood is “. . . a standing or status that is bestowed upon one human being by others, in the context of relationship and social being” (p. 8). This conceptualization of personhood is rooted in social interactionist theory that posits that the existence of the human self hinges upon successful interaction with others (Cooley, 1972; Kitwood, 1997; Mead, 1970). Arguably, persons with PMD often are not perceived as “others” with whom interaction is possible because they cannot demonstrate the putative cardinal human attributes of *co-presence* and *reciprocity* (Waksler, 2006). Co-presence (or social presence) is a form of human colocation in which individuals become “accessible, available, and subject to one another” (Goffman, 1966, p. 22). In the context of mediated human communication, co-presence is the subjective experience of being together with another person (Durlach & Slater, 2000; Zhao, 2003). Reciprocity is the mutual influence of individuals upon one another’s actions (Goffman, 1959). Demonstrating reciprocity during an interaction not only conveys information about the partner and the relationship, but also has “symbolic value” because it creates affective bonds between the actor and the partner (Molm, Schaefer, & Collett, 2007). In a dyadic interaction, co-presence

and reciprocity develop when one party responds to the actions of the other and is able to observe his or her responsiveness. For persons with PMD, who are unable to engage in intentional communicative interactions, the development of reciprocity and co-presence is highly problematic; as a result, they may not be accorded full personhood by those with whom they interact.

Interactions that affirm personhood create feelings of closeness and intimacy, which are essential for health and well-being (Baumesiter & Leary, 1995; Cacioppo & Patrick, 2008). However, converging evidence indicates that persons with PMD and their caregivers may not engage in personhood-affirming interactions. Due to the medical complexity of their conditions, many live in long-term care institutions, where residents with less-developed communicative skills and activity levels receive less positive contact from caregivers and more custodial care (Emerson et al., 2000; Hatton, Emerson, Robertson, Henderson, & Cooper, 1996; Seys, Duker, Saleminck, & Franken-Wijnhoven, 1998). Caregivers who are unfamiliar with a person with PMD are often unable to perceive and interpret the subtle non-intentional signals that convey his or her emotional state and responses; thus, interactions are characterized by neutral affection and instructions and are often confined to nursing, therapies, and medical care (Fornefeld, 1998; Seys et al., 1998; Vlaskamp, 1993). These interactions result in a lack of connectedness with and increased social distance between staff and patients. For persons with PMD, interactions with professionals, co-residents, and family members constitute a significant percentage of the social interactions they experience in their lifetimes (Campo, Sharpton, Thompson, & Sexton, 1997). Thus, improving the quality of these interactions has the potential to significantly improve the quality of life for persons with PMD.

We propose that converting the autonomic nervous system signals of a person with PMD into music – herein referred to as *biomusic* – has the potential to enrich his or her interpersonal interactions. In turn, these biomusic interactions may provide a foundation upon which family members and caregivers can accord people with PMD personhood (Blain & McKeever, 2011). Using physiological signals as a source of information about physical and emotional states is not unusual for those caring for persons with PMD. Clinicians, primarily nurses, commonly use cues such as heart rate, blood pressure fluctuations, and ventilator asynchrony to interpret needs and responses, especially pain (Happ, 2000). Physiological signals have also been used to interpret emotional responses in people with PMD (Kingsnorth, Blain, & McKeever, 2011; Vos, De Cock, Petry, Van Den Noortgate, & Maes, 2010).

The potential for using physiological signals to represent emotion has been well established (Bradley, 2009; Cacioppo, Berntson, Larsen, Poehlmann, & Ito, 2000; Gomez, Shafy, & Danuser, 2008; Hubert, Wicker, Monfardini, & Deruelle, 2009; Kring & Neale, 1996; Lang, Greenwald, Bradley, & Hamm, 1993). Additionally,

recent evidence suggests that physiological signals have the potential for creating a sense of connectedness or intimacy when revealed to another person. For example, Janssen and colleagues demonstrated that the auditory perception of an individual's heartbeat by another person influences social behavior in a similar manner as traditional intimate signals such as gaze and interpersonal distance (Janssen, Bailenson, IJsselsteijn, & Westerink, 2010). While music derived from physiological signals has previously been used for the purposes of artistic expression (Arslan et al., 2005), stress reduction (Yokoyama et al., 2002), and patient monitoring (de Campo, Hoeldrich, & Eckel, 2007), the effect of manifesting physiological signals through music to create a sense of social relatedness has not been investigated. However, music has a long-established history of creating emotional relatedness (Wood & Smith, 2004) and has successfully been used to create interaction with non-communicative persons (Graham, 2004). Exploiting this potentially potent combination, we developed technology that instantaneously converts continuous physiological signals of persons with PMD into biomusic. This study provides proof-of-concept (i.e., demonstration of feasibility and potential) and insights pertaining to the following research questions:

- (1) What types of relationships and modes of interaction do caregivers develop when interacting with persons with PMD?
- (2) How does biomusic affect caregiver perceptions of their interaction with persons with PMD?

Research Methodology

To maintain consistency with the social interactionist perspective of personhood (Cooley, 1972; Kitwood, 1997; Mead, 1970), we adopted a method that could facilitate the observation and analysis of social interaction. Our unit of analysis consisted of three clusters, each constituted by a person with PMD and his or her team of caregivers. Using qualitative techniques, this theoretically deductive, descriptive, exploratory study examined the interactions and relationships that occurred within these three clusters, both prior to and following the introduction of biomusic.

Setting

This study took place at the Complex Continuing Care (CCC) unit of a Canadian urban pediatric rehabilitation hospital. The children and young adults served on this unit typically have severe disabilities that require frequent and ongoing specialized care. Many are dependent on sophisticated medical technologies such as ventilators and feeding tubes for survival, and most have lived in the unit for months or years. Residents range in age from less than one year to adults in their mid-20s (awaiting transfer to adult facilities). Most occupy

four-person, shared rooms that are bright and modern. Efforts have been made to decrease the institutional feel with color and decorative elements such as colorful artwork, stuffed animals, family photographs, and religious items. The unit is usually bustling, as children and youth who are more mobile use their motorized wheelchairs to visit friends, nurses, and staff. Parents and other visitors generally populate rooms and hallways at all times of the day and evening. Many of the children attend the facility-run school and participate in facilitated arts, crafts, and music sessions held in the unit's family lounge or in children's rooms. Children's music can often be heard, while top-40 hits are popular in the rooms of teenagers and young adults. Sounds of monitors, ventilators, and suction devices are a constant part of the unit's soundscape. All of the biomusic interactions in this study took place amid this soundscape in the previously described patient rooms.

Clusters

Persons with PMD living in the CCC unit who met the following criteria were selected to participate in this study: (a) have a Rancho Los Amigos Cognitive Level ranging from I–III and are unable to physically or verbally express themselves; (b) are an inpatient of the CCC Unit; (c) receive routine visits/care from a parent, volunteer, nurse, or therapeutic recreationist; (d) have fingers large enough to attach the physiological sensors (i.e., 7 years or older); (e) have had prior exposure to and neutral and/or positive reactions to music; and (f) have a parent or guardian who gives proxy consent. A total of three persons with PMD met these inclusion criteria, and ranged between 12 years and 27 years of age. For each participant, a set of three or four of his or her caregivers was recruited for participation. To be eligible, caregivers were required to routinely visit the participant at least once a week and to have normal or corrected to normal hearing. Attempts were made to select caregivers who represented the most frequent interaction partners in the participant's long-term care: parents, nurses, therapeutic recreationists, therapeutic clowns, and art therapists. In the context of this study, each caregiver interacted with only one of the three participants with PMD. Ethical approval was received from the Research Ethics Board of the paediatric rehabilitation hospital, and written consent was obtained from each of the participating caregivers; parents as substitute decision makers consented on behalf of the persons with PMD.

To preserve the anonymity of the persons with PMD who comprised the center of each cluster, they are discussed using pseudonyms and limited detail. Thomas, Joanne, and Fred had each lived in the CCC unit for over 2 years at the time of the study. All three spent the majority of their day in bed, but occasionally spent time in a wheelchair, either to be transported to somewhere specific in the unit or for therapeutic purposes. Each required a ventilator in order to breathe,

Table I. Caregiver Characteristics.

Participant with PMD	Caregiver #	Cluster	Gender	No. of years in role	Routinely attends to physiological signals
Thomas	C1	1	M	2	No
	C2	1	M	17	No
	C3	1	F	13	Yes
	C4	1	M	8	Yes
Fred	C5	2	F	18	No
	C6a	2	F	5.5	No
	C6b	2	M	7	No
Joanne	C7	2	F	33	Yes
	C8	3	F	27	No
	C9	3	F	4.5	Yes
	C10	3	F	2	Yes

was fed through a nasogastric tube (NG tube), and was incontinent. They attended a school in the rehabilitation facility for several hours each weekday, and often participated in therapeutic recreation programs in the evenings; outside of these activities, their involvement in formal programs (e.g., therapies) was minimal. The parents of each these persons with PMD visited daily, often for several hours at a time. The clusters formed around each of these persons with PMD were:

- Cluster 1: Thomas, a parent, two therapeutic recreationists, and an artist;
- Cluster 2: Fred, a parent, two therapeutic clowns (working in duo, thereby considered a single caregiver), a nurse; and
- Cluster 3: Joanne, a parent, one therapeutic recreationist, and a nurse.

The characteristics of the caregivers of persons with PMD are presented in Table I. Throughout the manuscript, to ensure anonymity, caregivers will be referred to by their caregiver number.

Biomusic

Each person with PMD's biomusic was created from the dynamic patterns of four autonomic nervous system (ANS) signals: (a) electrodermal activity (EDA), which measures the amount of sweat present in an individual's skin and exhibits sharp changes 1.5–3 s after

an arousing stimulus; (b) fingertip skin temperature, which increases or decreases gradually approximately 15 s after an emotional or physiological stimulus; (c) blood volume pulse (BVP), which reflects changes in both the amplitude and rate of blood flow through the body; and (d) respiration, which responds to states of stress and relaxation (Blain, Chau, & Mihailidis, 2008). With the exception of respiration, all of these ANS signals reflect involuntary responses to physical, emotional and mental changes within an individual. These signals were monitored via four non-invasive sensors from Thought Technology™ that were applied as follows: Three sensors were secured with Velcro to different fingers of the left hand – a pair of EDA sensors to the medial phalange of the second and third fingers; one skin temperature sensor was applied to the distal phalange of the 4th finger; one BVP sensor was applied to the distal phalange of the 5th finger; and one elastic respiration sensor was loosely secured around the participant's thoracic cavity. Signals were sampled at a frequency of 256 Hz, and salient features were extracted in real-time from each signal with a custom-made software program.

The custom program immediately transformed the four ANS signals into four musical elements: EDA drove the melody, skin temperature changed the musical key, BVP drove the tempo, and respiration dictated the musical articulation/phrasing. A summary of the relationship between ANS signals and the musical elements is presented in Table II.

Biomusic created from the custom program was computer-generated, with output sounds generated using MIDI, and were often distinguishable between different people (every individual has an idiosyncratic pattern of physiological responsiveness). It is worthwhile to note that in mapping ANS signals to music, we deliberately avoided manipulating musical elements with strong emotional associations (e.g., major modes and consonance are universally associated with happy and pleasant emotions; minor modes and dissonance are universally associated with sad and unpleasant emotions (Fritz et al., 2009)). Without the ability to validate the connection between biomusic and a person with PMD's emotional state, our decisions were motivated by the ethical concerns of inappropriately using

Table II. Creating Biomusic from Autonomic Nervous System (ANS) Signals.

ANS signal	Feature extracted	Musical element controlled
Electrodermal activity	Average EDA over 0.25 s	Pitch: Notes of the melody, represented by "goblins" midi-sound, increase or decrease one semitone in pitch, with a respective positive or negative EDA change of 0.01 μ S.
Skin temperature	First derivative of signal over a 1s window	Key: A pedal point tonic chord is transposed up (e.g., from G to A) or down (e.g., from G to F), with a respective increase or decrease of skin temperature slope.
Blood volume pulse (BVP)	Period of signal over a 1 s window	Tempo: An underlying drumbeat and the frequency of the melody notes increase or decrease in response to heart rate.
Respiration	Period of signal over a 5 s sliding window, incremented in 1s intervals	Articulation: Melody and chords are presented legato throughout a breath and become silent at the end of a breath, creating musical phrasing.

biomusic to indicate more than the occurrence of a physiological change.

Biomusic Intervention/Data Collection

Within each cluster, caregivers participated in four individual biomusic sessions with the participant with PMD. The timing of these sessions was dictated by participating caregivers' routine visit schedules, and thus was unique to each participant. For some participants (C3, C4 and C7), biomusic sessions took place on the same day; for the others, they occurred weeks apart. During each biomusic session, the participant with PMD was either in bed or in a wheelchair in his or her room. ANS signals were recorded silently for 5 min to allow transient physiological patterns to settle, and then made audible in the form of biomusic for 5 min to allow the person with PMD to habituate to the sound. Following this habituation period, caregivers were invited to enter the room to interact with the person with PMD as they normally would while the real-time biomusic was generated softly in the background. Standard care and typical interaction were not manipulated. As the effect of the biomusic on the person with PMD and the caregiver were unknown, for ethical reasons, each interaction lasted no more than 10 min.

Interspersed among these biomusic sessions, caregivers participated in three open-ended, semi-structured individual interviews. The researcher conducting these interviews had no prior relationship with either the persons with PMD or their caregivers; had expertise in

introductory and advanced qualitative methodological techniques; and had experience conducting focus groups, field interviews, and personal interviews. The first interview occurred prior to all biomusic sessions, the second occurred after two biomusic sessions, and the third occurred after all four biomusic sessions. Interviews typically lasted between 15 and 30 min and were conducted in a private location. Due to technical difficulties experienced with the physiological sensors during some biomusic sessions, data from the second interview, which gathered caregiver impressions of the aesthetic quality and sound of the biomusic itself, were not analyzed.

The pre-biomusic interview focused on the types of relationships and modes of interaction that caregivers had developed when interacting with a person with PMD. Interview questions gathered information about typical visits, the ways in which caregivers communicated with the persons with PMD, and how the caregivers felt about their interactions. The post-biomusic interview focused on caregiver's perceptions of how biomusic influenced their interactions. Interview questions gathered information about the caregivers' perceptions of the sounds, the effect of the biomusic on their interactions, the effect of the biomusic on their perceptions of the persons with PMD, and their opinions of the concept of biomusic. Additionally, caregivers were given the option to turn the biomusic on or off during the third and fourth sessions and were asked to explain the reasons behind their choice during the interview. Complete interview questions are provided in Table III.

Table III. Interview Questions.

Interview	Questions
Pre-biomusic	<p>Tell me about your relationship with < person with PMD>? How much time during the week do you spend with < person with PMD>?</p> <p>When you are with < person with PMD>, what do you usually do?</p> <p>When you are with < person with PMD>, what do you hear? Are there any sounds in particular that you associate with < person with PMD>? Can you tell me about them? What do you see when you look at < person with PMD>?</p> <p>How does < person with PMD> communicate with you? How do you know if he/she is happy? How do you know if he/she is unhappy?</p> <p>How do you communicate with < person with PMD>?</p> <p>When you are with < person with PMD>, what gives you the most satisfaction? What is the most challenging about your time with < person with PMD>?</p> <p>Is there anything else you would like to tell me to help me understand the relationship you and < person with PMD> share?</p>
Post-biomusic	<p>Tell me about the sounds you heard during your visits with < person with PMD>? Did you notice any changes in the sounds during your visit? Do these changes (or lack of changes) have any meaning to you?</p> <p>Did you feel the sounds were connected to < person with PMD>? If yes/no, why?</p> <p>How did you feel listening to the sounds?</p> <p>Did the sounds influence you and < person with PMD>'s routine activities? If yes, in what way? If no, why?</p> <p>Did you feel that you influenced these sounds? If yes, in what way? If no, why not?</p> <p>The first time we talked, I asked you to tell me about < person with PMD> and the relationship you share. Did listening to the sounds created by < person with PMD>'s body change how you feel or think about him/her? I also asked you to share with me what you found rewarding and what you found challenging when you spent time with < person with PMD>. Did listening to the sounds created by his/her body change these perceptions in any way?</p> <p>Can you tell me about the choice you made to leave the system on or turn it off? What influenced your decision?</p> <p>Do you think it is a good idea to transform body signals into musical sounds? If yes, how could you see yourself using this in the future? If no, how could we make it worthwhile?</p>

Data Analysis

Interviews were transcribed verbatim; analysis of the transcripts was supported by qualitative research software (NVivo 8²). All members of the research team reviewed the transcripts in full and participated in the analysis. A team member with training in qualitative methods used the constant comparative method (Corbin & Strauss, 2008) to examine similar emerging themes in the transcripts of the 10 caregivers. Initially, open coding was used by all researchers individually to code all transcripts (Corbin & Strauss, 2008). This involved assigning a word or phrase to capture the meaning of lines or phrases in the transcripts. These open codes were reviewed by the team for commonalities and differences; codes were refined until consensus was reached. The transcripts from each cluster were assigned to two members of the research team to independently and individually micro-analyze the data line by line, and to manually apply open codes to chunks of data in order to describe content. Discrepancies in coding were resolved by discussions among the research team. Axial coding was then used to group and assign the open codes to four descriptive labels, which were derived from the study's research questions (Corbin & Strauss, 2008).

The first research question, What types of relationships and modes of interaction do caregivers develop when interacting with persons with PMD?, was subdivided into two categories: (a) Relationships and characteristic interactions, which included caregiver attitudes and feelings towards the person with PMD, as well as their typical activities with the person with PMD; and (b) Modes of interaction, which included typical strategies that caregivers used to send to and receive information from the person with PMD. The second research question, How does biomusic affect caregiver perceptions of their interaction with persons with PMD?, was subdivided to form the next two categories: (a) Perceived responsiveness of biomusic during interactions, which included perceived characteristics of the biomusic and descriptions of when, how, and why it changed or did not change during interactions with the person with PMD; and (b) Perceived impact of biomusic on interactions, which encompassed all descriptions of changes in caregiver behavior, attitudes, or feelings as a result of the presence of biomusic. Detailed notes were maintained for an audit trail. Finally, categories were examined and discussed with respect to Kitwood's conceptualization of personhood (Kitwood, 1997).

Results

Thomas' Cluster

Relationships and Characteristic Interactions with Thomas.

Thomas' sessions were characterized by a high degree of uncertainty for all of his participating caregivers. Thomas was an adolescent who acquired a traumatic brain injury

2 years prior to the beginning of his participation in this study. His caregivers were still searching for a reliable means of communicating with him. Caregivers cited the lack of certainty as the biggest challenge about knowing Thomas. This was illustrated by such comments as, "[It's challenging] not knowing if what we're doing is something that he truly wants to keep on doing, or if it's something he'd rather change" (C3); and "Well, it was hard again because I'm not sure how to read his responses" (C2). Thomas's inability to communicate made it difficult for caregivers to know what he perceived and understood: "I talk to him about random things. 'Do you recognize me? I am your [parent]'" (C1); and "You're coming in [to the room] and you aren't really sure if they know that you're there" (C2).

Thomas' caregivers described how they all were attempting to teach Thomas to raise his right hand to intentionally communicate "yes" in response to a question that usually involved a binary choice. Caregivers assumed that the absence of a raise indicated "no." Thomas did not produce this response consistently, sometimes raising his hand at inappropriate times and sometimes failing to raise his hand when expected to do so. As a result, different caregivers attributed different levels of intention to this behavior: "It's still hard to say if he's really doing it on purpose by saying yes" (C4). "I think it's just hard to know what his clear, for sure definitively, what his yes's and no's are" (C2). However, efforts made by one caregiver to develop effective communication strategies were generally supported and reinforced by the others in the cluster: "You know, one of the things that the school's been working on is the raising of his arm for yes or no, but even though that's inconsistent. . . You encourage kind of and see what Thomas's reactions are to certain activities" (C3). Caregivers clearly valued this form of more definitive communication. In response to a question regarding what he found most satisfying about spending time with Thomas, one caregiver responded, "Well, when he says 'yes' [by raising his arm]!" (C4).

Modes of Interaction. The majority of Thomas's behaviors as reported by his caregivers were classified as Level 1 in the Communication Matrix (pre-intentional behavior), with a small inconsistent Level 2 subset (intentional behavior) (Rowland & Fried-Oken, 2010). Participants tended to augment their interaction with Thomas by relying on their impressions or intuitions of what he might be feeling. Many of their interpretations were derived from subtle idiosyncratic changes in his body:

I just have a feeling when he is happy or sad. I just feel whether he is happy or not from the ways his eyes move. I can tell by his facial expression, sometimes, if he is unhappy he will just move. If you are washing his face and he doesn't want it, he will move you away. (C1)

Two participants interpreted Thomas' muscle tension as an expression of dislike: "It didn't seem to me he was

interested in doing hand-over-hand, like if I noticed there was a lot of resistance or he was really tight” (C2). “You know he does kind of stretch and tense up sometimes during certain things and so he becomes very rigid” (C3). They also thought that when Thomas was calm, he seemed to have less respiratory distress: “Thomas does have a really good cough, but I do know that in certain activities or when he’s most relaxed, he doesn’t seem to need as much suctioning, or he doesn’t seem to cough as much” (C3). “He coughs a lot if he doesn’t, you know, he doesn’t like what you’re doing” (C4). Overall, participating caregivers said they had become sensitive to changes in Thomas’s body, and seemed eager to try to attribute these changes to how Thomas was feeling in order to improve communication with him.

Perceived Responsiveness of Biomusic during Interactions. When Thomas’s biomusic was introduced in otherwise routine visits, the reactions of participating caregivers were varied. Impressions of the biomusic ranged from “too much” and “a little bit disturbing” (C2); to “soothing” (C4); “amazing”, and “exciting” (C3). Three of the four caregivers described how strongly they believed that biomusic provided information about and expression of what Thomas was thinking and feeling. His parent said that changes in the music represented Thomas’s response to his presence:

When I go in and the music is down, the sound seems to be longer. When I was at the door, the sound was softer. When I was there [at the bedside], it was longer and louder. I am not clear but I think that Thomas knows that there is a presence of a loved one. I assume this...I thought the sound was much longer and louder, just like a boy who jumps up when he sees his [parent]... I’m quite sure, because whenever I am near, it’s loud. Little bit longer, little higher. (C1)

One of the staff who worked with Thomas perceived changes in the biomusic, but did not connect changes to Thomas’s state and feelings:

Visually nothing seems different, but the sounds seem different, or it was different for sure, but I couldn’t really tell if [Thomas] had changed at all... so it was hard to understand or make a connection to why the sounds might be changing. (C2)

The remaining two staff connected changes they heard in the biomusic to changes in Thomas’s state and considered them a form of unintentional communicative interaction: “When he’s more spastic, I hear that the music is a bit louder, so I tend to not push it more” (C4).

During the Snoezelen [multi-sensory therapy], when I was doing hands on with him, and I noticed the intensity, I kind of realized that it was connected with [Thomas], but oth-

erwise it was just kind of music playing in the background. Until you notice the change in it, then you realize that it could be connected. (C3)

Perceived Impact of Biomusic on Interactions. All participants reported that biomusic affected the dynamics of interactions with Thomas. For one caregiver, the biomusic increased both her awareness of Thomas’s reactions and his responses to her behavior:

When you notice it increase in intensity you’re a little bit more self-conscious or conscious of what you just did that could have caused the change and therefore caused the change in the music. So I guess maybe it increased my observance of Thomas, or made me think of what I was doing in that moment that could have affected him some way. I think for tonight, especially like when I saw his pursed lips which is something that I interpret personally as being a discomfort, or maybe a dislike for something that’s happening and the fact that I heard the chimes increase, it made me a little bit more aware of that, so maybe it confirms that for me that that pursing of the lips is him reacting in some way... The music could be an indication of smaller changes and make you more aware of the way his body is, or certain body language. Having a way of knowing if we’re making changes within our clients, or if our presence is known, I think is absolutely amazing and really very exciting. (C3)

For Thomas’s parent, the biomusic provided a sense of Thomas’s character that he felt had been lost when Thomas became disabled. He did not use biomusic to gain information about Thomas’s moment-to-moment reactions, but considered them manifestations of the personality that Thomas had retained since infancy:

It makes me feel like before [his disability] when he was very lively. It makes me think of the lively boy before. The sound represents his character... I would want to have it on. The sound keeps on; it feels like my son still exists. I choose things for my son’s sake. For me, the song represents his heartbeat. (C1)

The other two caregivers were supportive of the biomusic because of the effect that it had on their own moods and the sense of meaning they experienced when they interacted with Thomas: “I think it could be very rewarding, but it could also give an additional sense of purpose” (C2). “It had a big role on myself, knowing how to deal with him. It calms me down – instead of being so silent, there is something right there” (C4).

Fred’s Cluster

Relationships and Characteristic Interactions with Fred. Fred was an older teenager who had been diagnosed as being in a “chronic vegetative state” (Laureys, Owen, & Schiff, 2004) as a result of a hypoxic brain injury that occurred when he was a toddler. He had a large family

who visited frequently and were “close” as described by his parent:

Ever since he’s been sick, his soul and my soul have become one... I see beauty. I think he’s beautiful, I think he’s really, really good looking. I’m proud of my good-looking son... I love the fact that he’s alive, I love holding his hand. I love smelling his hair. I just love being with him... If he dies, part of me will die. (C5)

In contrast, the other members of this cluster revealed that the communication barriers made it difficult for them to define Fred’s unique personhood and their connection with him. “It’s just a nurse to client relationship” (C7). Interactions were often brief and characterized by a great deal of uncertainty and confusion:

So I get the feeling from the team and just from my own perspective what I see and what I feel with him, is that it’s you’re fighting sadness a lot, you’re fighting frustration a lot... and you’re, you’re basically in a dark room stumbling around, trying to find some, some light, that’s how I feel when I’m with him. I’d say we don’t really have much of a relationship with him in the sense that we don’t know what our connection with him is. (C6)

Modes of Interaction. Fred had a severely limited repertoire of behaviors, all of which were classified as Level 1 (pre-intentional behavior) in the Communication Matrix. One caregiver explained that Fred did not appear to have any established way of interacting with other people:

There have been conflicting reports about how much he can sense or how much he can hear, or how much he can see, does he see anything at all? He’s basically in a coma state, and it’s a very difficult place to be as a practitioner. (C6)

Any responses that Fred could produce were inconsistent or difficult to interpret: “He’ll sigh... if I hug him, he’ll respond to me like... I’ll feel a hug back. If he’s upset, his body shakes – he’ll have a seizure” (C5). Auditory and visual interactions with Fred were, for staff members, characterized by silence and stillness: “I hear the beep of the machines... I see his sightless eyes... I see no movement, I see stillness” (C6).

While there was a desire and effort described with respect to finding a way of interacting with Fred, his caregivers had not found a way of doing this:

There has never been a consistent readable pattern that I could rely on as a practitioner, to give me an indicator that he’s aware of me; that he is responding to me. I’ve been doing a lot of reading of his heart monitor, just to see if the numbers corresponded. At one time we thought maybe there was a correlation to the touch, and his name, and the

numbers going up, the heart rate going up. But, that wasn’t consistent... I would say that in spite of efforts, there’s still no discernible pattern. We’ve asked [other] staff, what else can we do for him, what would you suggest and we’re getting a lot of soft smiles, and we’re getting a lot of ‘I think just doing what you’re doing is fine,’ nothing very specific, nothing formative. (C6)

Caregivers found that the most frustrating and challenging aspects of working with Fred were not knowing what he was thinking and feeling and his lack of communicative cues.

Perceived Responsiveness of Biomusic during Interactions and Perceived Impact of Biomusic on Interactions. Fred died midway through the data collection phase of this study, before the post-biomusic session interviews had been completed. Only one staff member completed all four biomusic sessions; what follows are the perspectives of this caregiver on the effect of Fred’s biomusic.

The caregiver described Fred’s biomusic as “soothing,” a “beautiful lyricism underwater mermaid song,” [sic] and a “helpful tool” that “supported the imaginative” (C6). However, the caregiver was not able to connect the biomusic to any change occurring with Fred. “I would deliberately try [to influence the biomusic] and I didn’t notice that there were any consistent results from that effort. I’m sure that the only way to know something like that is a lot of repetition” (C6). This participant supported the presence of biomusic, and expressed enthusiasm for using it as a tool in future interactions with Fred. “It was delightful to hear something connected to him – it was just a big treat. But I don’t know what it means... It’s helpful because it fills the space. It fills the silence.” (C6)

Joanne’s Cluster

Relationships and Characteristic Interactions with Joanne. Joanne was a young adult who was diagnosed in early childhood with pervasive developmental disorder. Interactions with Joanne were described as comfortable by her participating caregivers. Participants typically referred to Joanne using nicknames or terms of endearment. Relationships with her family were characterized by descriptions of affection. For example: her parent said, “I think we have a great bonding. She looks forward to me coming every night... She’s very loveable. She’s a very sweet girl and we get along really well” (C8). Her parent also described how Joanne’s siblings often visited her: “They’re teenagers... they have better things to do, but no, they still come. They care about her. If they don’t come, the minute I walk home, I walk in the door, they’ll ask me, ‘How is Joanne?’ and they want to know everything” (C8). Caregivers particularly remarked about Joanne’s smile and laughter. “I notice some of the nurses, they go, ‘Joanne, I am not leaving until you give me that smile. I want all teeth, all teeth’” (C8). “I’ve noticed that she’s been smiling a lot, and it

could be because she recognizes me, she recognized my voice” (C9). “I remember this one time in the evening shift, was around 10:30, and I go do my last check up and turn and change. And I went up to her and she’s laughing away there. I like that. I like that” (C10). Possibly as a result of her family’s frequent presence and the artifacts and information they provided, Joanne’s pre-disability personality continued to influence her daily interactions with her caregivers:

I always look at her pictures by her bedside and you always look at how they were and how she was, and what she is now, and it’s kind of sad. . . You kind of just look over the whole history and what the person is and then you kind of just get into routine so much that you concentrate on getting all these things done, but then sometimes you look back and say hey, she used to be like that, and she’s like this now, and it makes a big difference in the way you care for somebody. (C10)

Modes of Interaction. Joanne consistently expressed both pre-intentional and intentional behavior (Level 1 and 2 of the Communication Matrix). Participants interpreted her smiles and laughter as indications of preference, and the violent shaking of her head and her body and her increased coughing and secretions as indications of displeasure. While these were fairly limited responses, her cluster of caregivers was able to transform them into gestures with specific meaning within the context of their shared routines. Communication and interaction took place through the mutual understanding of the details of a task at hand. For example, her parent described how Joanne was able to use these responses to communicate more complex messages:

Now every Friday night, I go [away]. She knows. She knows it’s Friday, that I’m leaving. You know what? She’ll just do stuff that I cannot leave. And I’m there longer. She’ll be coughing, I have to keep suctioning her, and I go ‘Joanne, no more. No more, stop, now.’ And she would. (C8)

One of Joanne’s caregivers also said she augments her ability to understand Joanne’s moods and feelings with her heart rate: “You can tell when she’s relaxed. It means her heart rate will be a little low. If she’s unhappy it’s the opposite way – her heart rate will go up” (C10).

While these forms of communication enabled caregivers to determine Joanne’s overall moods, they were not clearly intentional, and all interviewees expressed a desire for a more definitive way of interacting with Joanne. For example: “One thing I find challenging is that she doesn’t have yet a definite yes or no response. . . Often times if she shakes her head we don’t know if she’s uncomfortable, or if that’s what she doesn’t want to do” (C9).

Perceived Responsiveness of Biomusic during Interactions. Joanne’s biomusic was viewed as a very positive addition to communicating with and understanding her by all members of this cluster. Joanne’s biomusic was described as “relaxing” (C8), “calming” (C10) and “phenomenal” (C8). Caregiver descriptions of their reactions included, “I’m totally amazed. I think it’s another way of interaction. The first time when I heard this, I had goose bumps. . . I wish I could hear more” (C8); and “I wonder what kind of sounds I would create” (C10).

Participants associated changes in the biomusic with changes in Joanne’s physical and emotional state. Some connected changes in the music directly to changes in her physiological signals: “I can tell she’s breathing a little faster, and then that’s how it changed the music” (C9). Participant C10 added:

I could almost hear this rhythm like a beat going, and then I was like ‘You know, that’s almost like that’s her heart beat’ and so I’d look at her heart rate [on the monitor]. Every time her heart rate would go up, that beat would go faster.

Others connected the changes to Joanne’s physical behavior:

I think the other times when she was really laughing and giggling you’ll notice the waves [of the biomusic], like up and down. . . When she was laughing, [Joanne’s sibling] goes ‘Mom, didn’t you see when she was laughing, the thing was going up!’ (C8)

There was actually one point when she was closing her eyes like till she’s getting really relaxed, and then I could hear a flute almost, or something like the piano, like at the higher end. And then afterwards when she starts to laugh, it changed so a lot more instruments, a lot of more variety, and texture. (C9)

These responses emphasized the importance of being able to correlate changes in the biomusic with a physiological or physical change of known significance to Joanne before a connection to the biomusic could be made. One of Joanne’s caregivers compared the effect of the biomusic between two sessions – one in which Joanne was behaviorally responsive and another in which she had appeared to be asleep: “So with this session I can now tell the sounds were connected to Joanne. Before, it was hard to tell because I didn’t see that variety” (C9).

Perceived Impact of Biomusic on Interactions. The perceived effect of the biomusic on the visits was varied. For one caregiver, the presence of the biomusic reinforced her interpretations of Joanne’s reactions to activities and events, as changes in the biomusic correlated with changes she saw in her behavior. Her parent appreciated the “evidence” that Joanne was actually responding to

her: “It’s not just somebody telling me, right? You know how they run tests and they go ‘This is the result,’ but I don’t know. So it’s being able to actually see something and experience it” (C8).

Biomusic also reinforced and augmented participants’ attributions of personhood to Joanne:

We still love her, care about her, advocate for her. I think this will make us even more connected.... with this music, I think there’ll be more connection. It tells me that, you know, she’s still there. She’s still connected. (C8)

It’s almost like she was trying to relate to you through her music... to us. But I’m thinking that was unique, like we sometimes, we forget as [caregivers] that you know we just kind of not look at the person, and just do what we have to do. This makes us step back and actually think about ‘Okay, so this is a person.’ She may be dreaming, she may be having some sort of thought, she’s not able to verbalize, but there are other ways [she] could probably give back to us. (C10)

Desire for Biomusic in Future Interactions

During the final interview, each caregiver that participated in this study was given a choice about whether they would like to use biomusic in future interactions with the person with PMD in their cluster. Of the eight caregivers who completed the third interview, six were enthusiastic about having biomusic as a part of their interactions. One caregiver did not want biomusic, as she did not like the sounds: “It’s more like sound or noise...today it was not pleasant, but last week it was much nicer” (C2). One caregiver wanted the option of being able to introduce biomusic into an interaction, but did not want it constantly present: “Half and half would be my preference. It really would be fun to do half a session leaving it on, and then turn it off and do the rest of it with it off or vice versa. It would be hard to choose all or nothing” (C6).

Discussion

In this preliminary study, we investigated the effects of biomusic on caregiver perceptions of their interactions with persons with PMD. By enabling caregivers to perceive physiological changes in persons with PMD through the medium of music, we expected to enrich their interactions and thus increase their sense of an individual with PMD’s personhood.

Interactions Between Persons with PMD and their Caregivers

In the first interview, before the biomusic intervention had been introduced to caregivers, we elicited descriptions of the characteristics of their interactions with persons with PMD. The range of described

interactions varied across clusters and across caregiver roles. Interactions between persons with PMD and family caregivers were consistently described as warm, and clearly demonstrated that these individuals were valued and cherished members of their families. This finding is consistent with research investigating the relationship between children with complex continuing care needs and their families (Carnevale, Rehm, Kirk, & McKeever, 2008; Emerson et al., 2000). Descriptions of interactions with other caregivers varied, ranging from the execution of pre-planned activities (e.g., arts and crafts, custodial care) to engaging in goal-directed interactions (e.g., working towards choice making by encouraging a physical response to a yes/no question). Regardless of caregiver role, interactions were consistently punctuated by the need to address the physical and physiological needs of the person with PMD, such as positioning and suctioning. All caregivers acknowledged the complexity of developing relationships with persons with PMD. None of the persons with PMD involved in this study exhibited behaviors that were clearly and consistently related to intentional communication, and the frustration and uncertainty associated with not knowing what the person with PMD was thinking or feeling was unanimously cited by caregivers as one of the greatest challenges of interacting with this population.

Reported Effects of Biomusic on Interactions with a Person with PMD

In their final interviews, caregivers described the effects of biomusic on their interactions with persons with PMD. In spite of technical difficulties that disrupted the sound of the system during some sessions, the response to biomusic was viewed very positively by a majority of participants. Caregivers in both clinical and personal roles with persons with PMD found value in the concept of translating physiological signals into music to enhance interpersonal interaction. Seven of the eight caregivers who completed the final interview felt that biomusic could have significant positive effects on their quality of interaction with the person with PMD in their cluster. The remaining caregiver found biomusic unpleasant to listen to, and was not interested in using it in future. Caregivers could be divided into two categories according to how the biomusic affected their interactions: (a) those who felt that biomusic was evidence of the person with PMD’s co-presence; and (b) those who felt that biomusic was a manifestation of the person with PMD’s responses to their actions.

Three of the seven caregivers who felt that biomusic had a positive effect on their interactions believed that it was a manifestation of the individual’s co-presence with them. These participants described co-presence in phrases like: “The sound keeps on, it feels like my son still exists” (C1). “It’s almost like she was trying to relate to you through her music” (C10). For some

caregivers, biomusic appeared to “re-present” the person with PMD, to make them more aware of his or her existence. Many said that they found this comforting and helpful for supporting their interactions with the person with PMD. Referring to Thomas’s or Fred’s biomusic, caregivers stated: “It had a big role on myself, knowing how to deal with him. It calms me down – instead of being so silent, there is something right there” (C4). “It’s helpful because it fills the space. It fills the silence” (C6).

Four of the seven caregivers who felt that biomusic had a positive effect on their interactions believed that biomusic was a manifestation of the person with PMD’s responses to their actions. It appeared that biomusic had this effect only if the person with PMD had some established, meaningful, physical or physiological form of responsiveness to others. Thomas and Joanne both had limited physical behavioral repertoires, but their caregivers attributed meaning to physical changes such as smiling, laughing, muscle tension, and frequency of coughing; and to physiological changes such as increased heart rate and respiration rate. Caregivers reacted most strongly to biomusic when changes in the music occurred simultaneously with one of these physical or physiological changes. Conversely, without an established communicative pathway, changes in biomusic could not be connected to participants’ reactions after exposure to four biomusic sessions.

This pattern was evident in all three clusters: Caregivers strongly connected biomusic to responses in Joanne, who demonstrated consistent affective behavioral responses; they drew more tentative connections between biomusic and Thomas, whose behavioral responses were subtle and inconsistent; and they were not able to connect the biomusic to Fred, who did not demonstrate consistent behavioral response to his environment. Some of Fred’s caregivers hypothesized that they might have been able to eventually draw connections between Fred’s biomusic and his responses, with much repetition of the same actions across many biomusic interactions. Caregivers indicated that biomusic helped them perceive the person with PMD’s responsiveness to their actions, by providing additional

evidence and manifestations of reactions, and by drawing attention to subtle behavioral changes, such as Thomas’s pursed lips, that caregivers previously had not considered communicative. Table IV summarizes the connection between each participant with PMD’s communicative behaviors and their caregiver cluster’s perception of biomusic.

Using Biomusic to Establish Personhood

The ability to interact and communicate with others is essential to ensuring adequate quality of life for people with severe and profound disabilities (Hewett & Nind, 1998) and, indeed, human beings in general. Without this ability, an individual’s personhood is threatened, and he or she is at risk of being perceived as merely “a body in a bed” (Gubrium, 1997, p. 123). However, a prerequisite for successful interaction is for individuals to perceive persons with PMD as “others” with whom interaction is possible – something that is possible only if they are attributed the putative characteristics of co-presence and reciprocity (Waksler, 2006). This study demonstrated that (a) caregivers perceived biomusic as a manifestation of a person with PMD’s presence with them; in other words, biomusic established the co-presence of the individuals with PMD; and (b) biomusic created caregiver awareness of a person with PMD’s responsiveness to their actions, which is a necessary condition for the development of reciprocity. By providing evidence of these attributes in apparently non-responsive persons, biomusic positively enhanced their personhood by re-presenting them as persons and changing the way caregivers interacted with them: “Sometimes, we forget as nurses and caregivers that we just kind of not look at the person, and just do what we have to do. [Biomusic] makes us step back and actually think, ‘Okay, so this is a person’” (C10). Most caregivers experienced changes in feelings of connectedness and the sense of a person with PMD’s personhood as a result of biomusic. These changes are likely to improve the quality of interaction and the quality of life of profoundly disabled persons of all ages.

Table IV. Comparison of Participants with PMD and their Caregiver Cluster’s Perception of Biomusic.

Person with PMD	Presence of hearing impairment, reported by parents & caregivers	Level of communication (Communication Matrix, Rowland & Fried-Oken, 2010)	Communicative behaviors	Caregiver cluster perception of person with PMD’s biomusic
Thomas	No	Level 1/2: Emerging pre-intentional behavior; emerging intentional behavior	Eye movements; facial expressions; muscle tension; ease of respiration	Provided information on thoughts and feelings; increased awareness of responses and reactions; provided sense of co-presence
Fred	Unknown	Level 1: Minimal pre-intentional behavior	Sighing; seizures	Unconnected to Fred; filled space and silence
Joanne	No	Level 2: Mastered pre-intentional and intentional behavior	Smiling; laughing; violent head/body shaking; coughing; secretions	Positive addition to interaction and communication; connected to state, emotion, and physical behavior; evidence of responsiveness

Limitations and Future Directions

The results of this preliminary study must be interpreted in light of several important limitations:

1. This study was conducted with a small, non-representative sample of participants. In that participating caregivers had an average of 9.5 years of experience interacting with profoundly disabled children/adults, they were able to seek and interpret subtle cues in persons who do not communicate in traditional ways. Most expressed positive excitement about the possibility of deepening their connection with persons with PMD. Hence, their accounts of and responses to a person with PMD's biomusic may not be representative of those who are not familiar with this population, or who do not have any interest in developing relationships with such persons.
2. The mapping of physiological signals to musical elements used to create the biomusic was not evidence-based. Varying the combination of physiological signal features and musical elements, or adding different musical elements (e.g., major and minor mode) to the biomusic may significantly alter the effect of the biomusic on the interactions in a cluster. Furthermore, the perception of music is strongly influenced by the age, culture, and context of the listener; this needs to be taken into account in future studies that use music to convey the affective state of an individual.
3. During several interaction sessions, we experienced technical problems with the physiological sensors. The electrodermal activity sensor that controlled the melody was particularly prone to detachment. Additionally, the sensitivity of this measure is largely dependent on blood flow to and temperature of the fingers. The physiological sensors were also particularly sensitive to any motion artifacts associated with spasticity and/or seizures. While these technical issues did not appear to affect participants' impressions of the concept of using biomusic in interactions with persons with PMD, the biomusic presented to several participants had missing elements.
4. Participants were instructed to interact with persons with PMD according to their typical routine while biomusic was playing, which required them to simultaneously perform the activity-at-hand and attend to the biomusic. While this is likely reflective of how biomusic might be used in a practical context, many participants reported anecdotally that it was difficult to concentrate on these dual tasks, and some found the task of finding a pattern in the biomusic overwhelming while attempting to maintain normal interaction with the person with PMD.
5. Each biomusic session was limited to 10 min; thus, each caregiver listened to a total of only 40 min

of the person with PMD's biomusic. The effects of biomusic described by caregivers in this study may be a result of its novelty and may change after periods of prolonged exposure.

6. The data collected in this study were limited to the subjective perspective of caregivers gathered retroactively through interviews.

These limitations inform future directions for the development of this promising technique of enriching interactions between persons with PMD and their caregivers. For example:

- Future studies should engage a larger number of diverse caregivers and persons with PMD of different diagnoses and in varied contexts, in order to better understand the value of this novel technique in a more generalized population. Future studies should also gather objective data, such as direct third-party observation and measures of a person with PMD's alertness and engagement (Vlaskamp & Munde, 2010), that could be triangulated with caregiver interview data.
- Focused exploration into the most effective physiological-musical mappings and greater flexibility to customize the biomusic to individual tastes and preferences might further augment the acceptability of this tool for diverse caregivers, and provide a more connected and individual manifestation of the person with PMD's affective state.
- Many of the technical difficulties experienced in this study resulted from the unobserved detachment of sensors when a participant moved; technologies that integrate physiological sensors into wearable devices and clothing (e.g., Ming-Zher Poh, Swenson, & Picard, 2010; Stead, Goulev, Evans, & Mamdani, 2004) could provide future comfortable and robust platforms for recording physiological signals for biomusic.
- Study participants expressed a desire for sessions where they could focus on the biomusic without the distraction of having to attend to another task-at-hand; future studies could explore the effect of biomusic on the relationship between persons with PMD and their caregivers in more controlled contexts.
- Longitudinal studies should be conducted to determine the long-term effect of biomusic and how its impact on interactions with a person with PMD changes with increased, repeated exposure. Valuable future directions also include studying the experience of biomusic from the perspective of the person with PMD, which could be accomplished by introducing biomusic as a tool for communicative interaction in individuals who are temporarily severely disabled (e.g., post-surgery patients before they are extubated, patients who have suffered a stroke or traumatic brain injury). These studies could also lead to insights facilitating the interpretation of biomusic and their use in defining specific

emotional responses, preferences and/or communicative intent.

Conclusion

Caregivers reported that biomusic provided a musical re-presentation of three persons with PMD with little to no ability to move, speak, or engage in traditional communicative interaction. The effects of the biomusic on caregivers' perceptions of their interaction with a person with PMD were varied. Some caregivers perceived biomusic to be a manifestation of the person with PMD's presence. If a person with PMD had a physical or physiological response that caregivers interpreted as communicative, many reported that biomusic provided further evidence of that individual's responsiveness to their actions. These effects of biomusic may be interpreted as the initial development of the sense of co-presence and reciprocity that is necessary to establish an individual's personhood. Indeed, some caregivers reported that biomusic served to increase the caregivers' feelings of connection and their sense of the person with PMD's personhood, which may ultimately improve the quality of life of both the person with PMD and his or her cluster of caregivers. These results support the continued study of biomusic as a means of revealing the personhood of some of the most vulnerable members of our society.

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Notes

1. Thought Technology: Thought Technology Ltd.; Montreal, PQ, Canada. www.thoughttechnology.com
2. NVivo software: QSR International; Melbourne, Australia; www.qsrinternational.com

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