

ARTICLE

Communicative musicality, music and transformation in the lives of parents and their children with cerebral palsy and multiple disabilities (CPMD)

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ABSTRACT

The births of children with cerebral palsy and multiple disabilities (CPMD) challenge their families' wellbeing. This article, which is based on a theme generated from an interview study, suggests that communicative musicality and the everyday use of music transforms these families' experiences. The research questions aimed to explore the musicality of individuals with cerebral palsy, and the use of music within their families. Six parents to individuals with cerebral palsy and multiple disabilities participated in this study. The data were collected through a three-interview series with each participant, integrated with home-video viewing. The interview transcripts were analysed with interpretative phenomenological analysis and grounded theory. Initially three core themes were generated (and presented in another publication). The 'transformation' theme is a fourth theme generated from a later analysis of the research interviews. It is presented here through the parents' voices as well as the researchers' interpretations. Theory and research are discussed on communicative musicality, everyday musicking, and wellbeing. We suggest that the families' intensive use of nonverbal communicative approaches, and music transformed their experiences: their moods, participation, and the meanings related to their lives together.

KEYWORDS

cerebral palsy,
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INTRODUCTION

The theme at the centre of this article, 'transformation', is a later addition to our study on children and young adults with cerebral palsy and multiple disabilities (CPMD)¹, their musicality and their families' everyday musicking (Roginsky, 2016). Six parents participated in the original study. Each parent took part in a three-interview-series, integrated with musical home-videos. The analysis employed interpretative phenomenological analysis and grounded theory. Three core themes were generated on communication, the use of music, and on parental knowing. These themes were described fully in a different research paper (Roginsky & Elefant, in progress). An additional theme was found but left unprocessed due to our lack of an appropriate theoretical perspective. Thanks to the Nordoff Robbins *Plus* conference 'Exploring the spiritual in music', an adequate frame of thought emerged and the missing theme was processed.

Below, a literature review is given on CPMD and parental experience, communicative musicality, and on the use of music with individuals with CPMD. Then, the methodology of our research study is described and the fourth theme, transformation, is presented.

CEREBRAL PALSY AND TRANSFORMATION

Cerebral palsy: Parental experiences

Cerebral palsy (CP) is a chronic, non-progressive condition, caused by serious damage to the young, developing brain (Oskoui, Countinho, Dykeman, Jette & Pringsheim, 2013). It might cause various degrees of functional, cognitive, behavioural disabilities, and epilepsy (Rosenbaum et al., 2007). Severe conditions of cerebral palsy involve expressivity and speech impairments that might lead to psychological and social barriers (Cockerill et al., 2013). These conditions are named here cerebral palsy and multiple disabilities (CPMD).

Parents to individuals with CPMD may often encounter high levels of stress (Parkes, Caravale, Marcelli, Francesco, & Colver, 2011), sorrow, and other psychological symptoms (Whittingham, Wee, Sanders & Boyd, 2013). The participants of a study on parents' experiences when their child was diagnosed with cerebral palsy portrayed their daily preoccupations: the unstable health of the children, their intensive care, and an on-going financial struggle (Ribeiro, Vandenberghe, Prudente, Vila & Porto, 2016). These parents, however, reported some adjustment and decrease of stress in later years, as the children matured and stabilised. Burkhard (2013) generated four essential themes on mothers' adaptation to their adolescents with CPMD: managing an unexpected life, finding my own way, serving as my child's voice, and facing an uncertain future. These themes reflected the parents' ability to transform their uncertainty and struggle into meaningful, compassionate living. Quite similar results were generated in our study on musicality and the use of music with children and young adults with CPMD (Roginsky, 2016; Roginsky & Elefant, in progress); the participating parents portrayed communicative musicality and musicking as central in their process of adaptation.

¹ This term addresses individuals with severe and extensive influences of cerebral palsy: sensory-motor, cognitive and more.

Communicative musicality, music, and cerebral palsy

Communicative musicality is the use of voice, mimicry, body motion, silence and halts, and the changing dynamics and organisation of these, through the ongoing interaction of parents and their preverbal infants (Malloch & Trevarthen, 2009). It also underlies every person's communication with others throughout life (Butterton, 2007). This term was coined by Malloch and Trevarthen, (Malloch, 1999; Malloch & Trevarthen, 2009), preceding the studies of Trevarthen (2015), on the meaning and essence of infants' expressive motion. Malloch and Trevarthen's analyses of parent-infant communications (2009), suggested that communicative musicality was essential for the development of subjectivity and sociability in children. A broad body of research supports that notion: reciprocity was found a regular characteristic of mother-infant communications (Brazelton, Koslowsky & Main, 1974). Babies' ability to imitate was found to afford the development of theory of mind (Melzoff, 2007). Connection was seen between communicative musicality and the quality of mother-child relations (Beebe & Steele, 2013), as well as the development of inter-subjectivity in adult relations, and psychotherapy (Ammanity & Ferrari, 2013; Butterton, 2007; Stern, 2010). Insufficient communicative musicality was also studied: babies of postpartum depressed mothers, whose expressivity and reactions were dull (Papoušek & Papoušek, 1992), or babies with developmental or health issues that failed in communicating with their parents, achieved inferior social skills (Papoušek & Von Hofacker, 1998).

Communicative musicality of individuals with cerebral palsy has not been researched extensively. However, evidence on the use of nonverbal communication with this target population is found in the music therapy literature. Gilboa and Roginsky (2010) noticed the contribution of musical improvisation to the development of attunement, mutuality and empathy during short-term therapy with a mother-child dyad. This dyad's attachment had been interrupted with the child's traumatic birth and cerebral palsy. In therapy the mother was taught through musical improvisation to be more engaged with her son's communicative musicality and play. Following therapy, her attunement with the child and their mutual involvement improved. McFerran and Shoemark (2013) described the rich nonverbal dialogues in music therapy with a non-speaking young adult with CPMD. The active use of this client's communicative musicality was reported as contributing to his sense of wellbeing. Thompson and McFerran (2015) studied the outcome of music therapy with three separate children with cerebral palsy and profound intellectual disabilities. The clients' nonverbal communications (greetings, responses to names, farewell acknowledgment) as well as their quality of attention improved following 21-27 music therapy sessions. These cases, we suggest, may imply that communicative musicality survived despite the clients' severe brain damage; in fact, communicative musicality was an influential means for interaction with the non-speaking individuals with cerebral palsy. The survival of communicative musicality despite CPMD, we argue, afforded musicking influence on our research families' health and wellbeing.

Research shows that the regular use of music can improve people's quality of life. MacDonald (2013), for instance, proposed five interlinking fields where music enhanced health: music education, music medicine, music therapy, community music, and also what he named 'everyday uses' of music – listening, viewing, and participating in musical activities of choice. MacDonald related much significance to this last field. It was described as affording self-awareness, self-regulation, security

and control. Relying on the works of DeNora (2000, 2010), MacDonald defined music as a human form of self-help.

The health perspective on music has been covered thoroughly by DeNora and Ansdell (Ansdell, 2014; Ansdell & DeNora, 2016; DeNora, 2013). Through theory and case study, these authors portray music as an affording medium, appropriated to furnish people's worlds according to their unique personalities, tastes and needs. The affordances of music are also apparent in cases of disability. Ansdell and DeNora (2016) described community music therapy at BRIGHT, a day centre for users of mental health services. At BRIGHT, music afforded personal and communal transformations: it encouraged participation and authentic expression. It supported people's strengths, and reinforced group cohesion. The transforming power of music was illustrated through the story of BRIGHT's singers' visit to a general hospital ward, where, though facing disability themselves, they tended sensitively to the musical needs of a patient who seemed near the end of his life (DeNora, 2013).

CPMD is yet a different condition, but the benefits of music in cultivating the health and wellbeing of individuals with CPMD are similar, as reflected through the work of music therapists. Neurological and functional music therapists use prescriptive interventions to improve the gait, speech, movement or learning of their clients with cerebral palsy (see, for example, Marrades-Caballero, Santonja-Medina, Sanz-Mengibar & Santonja-Medina, 2018; Nami, 2017; Thaut, McIntosh & Hoemberg, 2015). Looking back at the 1960s and 1970s, pioneering music therapists seem to have held more holistic perspectives towards the treatment of clients with cerebral palsy: Juliette Alvin (1961, p. 261) tried to reach "emotional freedom, social and cultural belonging" with these clients. Interestingly, a few years later, in *Music for the Handicapped Child* (Alvin, 1965), her view had become rather rehabilitative. Quite differently, Nordoff and Robbins music therapy did not focus on clients' diagnoses or their functional rehabilitation, but on their 'music child': "the organizing agent that gives response or activity its integrity, its originality, its unique meaningfulness, its message of individual human presence [...] Within an awakened music child, the being child moves toward fulfilment and completeness" (Nordoff & Robbins, 2007, p. 17). Aldridge explained in an interview:

Whatever the other person is doing, whomever you are sitting across from, whatever smallest movement they do, whatever gesture, whatever sounds they used, we use that and base the music that we make with them on that... everyone is seen as a 'music person', there aren't inherent differences in the music based on age or condition. (Aldridge, cited in Mahoney, 2016, p. 14)

Various documentaries by Nordoff Robbins music therapy graduates with individuals with cerebral palsy (for example, Nordoff Robbins, 2008, 2016) demonstrate the vitalising effect of playing, vocalising and moving, and humane treatment in directing these clients towards reaching their abilities and personhood, and towards their families' wellbeing. Through our participants' experiences, the present paper follows a similar thought – that everyday musicking may have served in those families as a fundamental means to transform their health and wellbeing, including the individuals with CPMD.

METHODOLOGY²

Overall, four research questions were formed:

- a. In what ways can parental experience enrich our knowledge about communication with their children and young adults with CPMD?
- b. How do parents use music with their children and young adults with CPMD?
- c. What purposes does music serve with these individuals?
- d. Can parents describe the meanings of music in the lives of these children and young adults?

Parents of children and young adults, ages 8-20, diagnosed with severe cerebral palsy and multiple disabilities (CPMD) were addressed. The participants were recruited through healthcare professionals and organisations for individuals with cerebral palsy. Six parents were recruited. All of them were thoroughly informed about the research aims and procedure, and signed the consent forms. Standard codes of ethics were implemented, as required and approved by the University of Haifa Ethics Committee.

Qualitative research was used to explore the parents' subjective experiences and meanings (Denzin & Lincoln, 2011). A Three-Interview-Series (Seidman, 2006) was conducted with each participant:

1. A semi-structured Life-World Interview (LWI) (Kvale & Brinkman, 2009) with a pre-composed script, focusing on the background of the families and their children and young adults with CPMD.
2. A semi-structured LWI, with a pre-composed script, integrated with the viewing of home video clips. Two topics appeared: the musical worlds of the families, and the musicality of the individuals with CPMD.

The interviews were held one month apart, and were audio recorded and transcribed in detail. Grounded theory analysis followed.

3. An open interview (Corbin & Morse, 2003; Seidman, 2006), in which the core themes generated through the grounded theory analysis were read together and discussed freely. Each participant could process and reconstruct their former ideas on the research topics: musicality, music and their children and young adults with CPMD.

Additional grounded theory analysis of each third interview followed, and a last grounded theory on the full body of data generated throughout the analytic procedure. A peer review was done by two cerebral palsy specialists (a physiotherapist and a speech therapist) on the final results.

An interpretative phenomenological analysis (Smith, Flowers & Larkin, 2009) took place from the beginning of this study, including planning through writing: the researcher's journal, the interviews and grounded theory analyses, as well as peer review, were part of the continual circulation of data collection and reflection. The aim was to reach an integrated theory (Linge, 2004) based equally on parental and professional knowledge.

² The research method is explained briefly as a fuller description of the data collection and analysis can be found in our full research paper (Roginsky & Elefant, in progress).

Three core themes were generated through the grounded theory procedures of analysis: communication, the use of music in these families, and the parents' knowing. The fourth theme, transformation, was processed and written at a later stage, after the completion of this study. The additional theme captured the participants' unique appreciation of their children's personhood, and it was reflected clearly through their descriptions of communication and musicking with these individuals. At the time, this theme was left unprocessed mainly due to the lack of a proper theoretical frame. A year later, having participated in the Nordoff Robbins *Plus* conference, *Exploring the Spiritual in Music*, an adequate frame of thought was offered through which we could re-examine the unprocessed theme. The present article came as a result of this later analysis; the freedom to explore, as well as a few main ideas and terms, are driven by the presentations and discussions at the Nordoff Robbins *Plus* conference on spirituality.

FINDINGS: THE TRANSFORMATION THEME

The transformation theme describes the everyday use of nonverbal communicative approaches and musicking as enhancing change in the families' experiences of caring for their children and young adults with cerebral palsy and multiple disabilities.

Four sub-themes portray the process, means and results of transformation: parental seeking and attunement, the proto-language established between parents and their children, and the paradoxical stances leading to appropriate music as a tool and container of change. The participants and their children's names, as well as any other identifying details, have been changed. They are presented here as the parents of Matanel, Roni, Tohar, Noa, Eli, and Lilly: children and young adults with CPMD.

Sub-theme 1: Seeking and attunement

The births of their babies with CPMD and atypical expressivity caused the research participants to take a path of ongoing search for meaning. Seeking and attunement afforded the parents to transform their unknowing and helplessness, and establish relations with these children. Constant seeking was repeated throughout the participants' stories: their babies faced life-threatening health conditions; these babies' survival was the parents' fundamental goal, yet their needs were unexpected and unknown.

Tohar nearly didn't cry unless she was in great pain. She wouldn't ask for anything, not even food. When Tohar had seizures she was completely isolated.
(Tohar's mother)

The search for meaningful communication was ongoing; it was, after all, the basis for relating with the children with cerebral palsy.

During her first eight months, Lilly didn't stop crying; she suffered aches and pains...that's how it is when children are born so small. (Lilly's mother)

There was no way to soothe this baby! His mouth was extremely sensitive and he couldn't suck. Rocking him only made things worse, so the stroller solution was out of the question; honestly, we had no way to calm this baby down! (Matanel's mother)

Individuals with CPMD are characterised by atypical expressivity: crying, laughing and vocalisation, can have unexpected meanings (Miller & Bachrach, 2007). The research participants were trying continually to comprehend their children and young adults with CPMD; careful attention was paid to their every motion and expression.

At NICU, you'd see her breath change, especially when she was very little; it would suddenly change when I got closer. (Toha's mother)

I can tell by Rony's expression; that's how I know she is content or she wants or doesn't want something. (Roni's mother)

She can talk with her smile! (Noa's mother)

They sit together a lot and Lilly...makes all kinds of voices when they are together; these voices he can understand. (Lilly's mother)

The parents' ongoing efforts to attune to their children and young adults with CPMD indeed resulted in improved comprehension. Some parents seemed to attribute themselves superior communicative abilities:

Someone who sees Tohar can tell me that she's static, or she cannot respond. The truth is that she DOES respond, but you should get to know her more intimately to notice that. (Tohar's mother).

Only a parent knows these things... (Roni's mother)

We can tell by the look on our children's faces or even by the blinking of their eyes. (Eli's father)

These parents portrayed their children's communications in much detail:

My daughter is magnetising! Her smile does that. She can talk with her smile...she has this special smile that means 'I want you near me!' Oh my god! This is her make-friends smile! I can't explain how, but it always works. (Noa's mother)

Brothers and sisters were also aware of their siblings' expressions, and would freely interpret them during family interaction:

As we drove to a family dinner the children were quarrelling over the music we should hear, and Noa let out this loud voice; 'Are you saying that I'm dumb?' her sister replied angrily - Noa just laughed at her. (Noa's mother)

The participants' intensive seeking and attunement resulted in establishing unique modalities of communication with the individuals with CPMD: they were based on body expression, on temporal dynamics, as well as on close acquaintances and deep faith in each child's aware, human presence.

Sub-theme 2: Proto-language

This sub-theme focuses on proto language: the nonverbal, very delicate and primary means of communication established within the research families. It was employed successfully by the parents and their non-speaking individuals, and helped to overcome the communicative barrier.

Understanding the individuals with a disability involved a constant pursuit for any of their proto-communicational signs: their autonomous motions and intentional expressions were studied and interpreted:

Look here, see? His breath is shallower now; that's how I know he is excited!
(Matanel's mother)

There, you can see that her body relaxes, her eyes become distant – the child is obviously somewhere else. (Tohar's mother)

Smiles, laughter, crying or vocalising were followed:

He has variations of laughter. There is this laughter 'yea, all right' directed to keep us content "(Matanel's mother).

Eli's private talk was treated as an official language:

We all know that 'LA-LA-LA' means that he wants to listen to music, and 'GA-GA-GA' is the telephone. We have a printed dictionary of all his words. (Eli's father)

Upon these motions and vocal signs, communicative musicality was established:

When Matanel sits in his room and someone at the living room laughs, he responds immediately with his own laughter as if to reassure that he's listening.
(Matanel's mother)

My husband makes all sorts of noises that Roni likes; he makes this sudden 'ATCHU!!' some sort of silly voices – and Roni – she melts! She faints! You can't believe what happens! What ecstasy and rolling laughter!! She simply cannot stop! (Roni's mother)

Lilly, another child, was recorded during an interview as she manipulated the whole family using her voice dynamically to make them come over and say “good night.”

These families were well-trained nonverbal communicators; yet this specialty was not owned by others outside the family. “At home we all understand, but as soon as he steps out of home, he is completely mute,” shared Eli’s father, and Roni’s mother complained: “No one else but their parents may understand.”

Sub-theme 3: Paradoxical stance – the mechanism of change

Paradoxical stance, according to Hart (2000), is a main characteristic of transformative processes. The parents’ experiences regarding the communication with their children with CPMD reflected significant paradox and its solution – the transformation itself. The paradox revolved around the parents’ opinions regarding their children’s communicability and personhood: a) they had faith in these children’s potentials; b) they were uncertain of the validity of this faith; c) they had seemingly unrealistic hopes regarding the potential development of their child’s communication, especially verbal communication.

The following descriptions, generated from a single interview with Matanel’s mother, may demonstrate the parents’ paradoxical stance where faith, uncertainty and hope co-exist:

When I see his eyes, I’m sure he understands much more (*faith*)

He does not make sense at all (*uncertainty*)

I still hope he reaches communication one day...language, yes, even words (*hope*)

A comparable paradox was noted as the parents were asked to assess their children’s musicality³, as shown in the examples below, drawn from Roni’s mother:

Roni loves sounds. There are a few sounds she prefers over others; she actually has a taste for sounds. [...] Roni adores that song...even more than the other songs known to her. She likes these as well, but some songs are really her favourite. (*faith*)

How would I know if she is musical? She doesn’t give the slightest hint. (*uncertainty*)

Interestingly, hope was not expressed regarding musicality. Additionally, musicking experiences were not found paradoxical at all. We would like to offer that the paradox found in the realm of verbal or more typical communication kept pushing these parents to seek less paradoxical communicative experiences with their individuals with CPMD. As a result, communicative musicality and musicking were encountered. However, they were merely points of relief, as the ‘seeking stance’, an unresolved paradox in nature, was still found the most stable parameter in relations with the children and young

³ The research participants were asked whether their children were ‘musical’, as they were overall unaware of the term ‘communicative musicality’.

adults with CPMD. Seeking was essential, as it kept the parents alert and open-minded, searching for entry points, reactions, shifts and changes in their children's expressions. Motivating this stance was the parents' vague intuition that within the great deficit some untouchable potential exists:

I know that my son has got something more in him, yet, we cannot reach it.
(Matanel's mother)

The paradoxical stance – their movement between seeking and finding, faith and disbelief – may, as Hart (2000) proposed, have provided the parents the power to go on exploring fuller communication and relations, despite their children's severe disabilities. Musicality and musicking, less paradoxical as seen, were employed for nurturing faith in these individuals' whole personhood.

Sub-theme 4: Living in music

Transformation in the realm of music is described now to a broader extent. Music provided these families an alternative for disability and isolation; it created a space that afforded cohesion, wellbeing, and a sense of health. Pleasurable moments were encountered in music.

Why do you ask me about the purpose of music? Is it not clear? LIFE IS MUSIC!
I want my child to have fun! (Roni's mother)

Music improved bonding between parents and children:

Can you see? She wants me to continue singing! That's great... see? Tohar listens to what I do! Did you notice that when I sang to her she replied vocally?
(Tohar's mother).

Family cohesion was enhanced through music:

When my kids turn the music on – It's wow! America! They love music so much!
They enjoy just listening, dancing and having a good time! (Noa's mother)

They can spend even an hour during afternoon just listening to music together
(Lilly's mother)

Disagreements also occurred around musical preferences:

[During a car ride] my elder child complained – “why must I suffer this Eastern music every time we stay together?! Why can't we listen to my style, to my songs for once?” (Noa's mother).

Play and creativity were facilitated with music:

When he was younger we would let him complete the last syllables of songs (Eli's father)

My elder child has a DJ editing station...when they stayed together once, Noa picked a song she liked and they edited it together... just for fun (Noa's Mother).

In music, the children and young adults with cerebral palsy could enjoy traditional holidays and ceremonies just like any other family member:

I let her listen to every holiday song (Roni's mother)

On Shabbat dinner when we chant, I take his hand and help him sense the beat so that he can feel our music...he always has this attentive face when we sing (Matanel's mother)

The families were also able to include their children and young adults in public musical events: "We go together to every children's song festival (Lilly's mother)

A while ago I took all my kids to a concert - the children, myself and a neighbour, see for yourself in that video, here, look at Noa: someone came over to her, a complete stranger, and they danced! They love it! (Noa's mother)

Musicking improved the families' wellbeing. It supplied the parents and their children more equality and an alternative space for communication, fun and play. With music, the families included their individuals with CPMD at home and in public. While musicking, the individuals with CPMD, as well as their family members, were not left out, weakened and disabled.

DISCUSSION: CEREBRAL PALSY, COMMUNICATIVE MUSICALITY, AND TRANSFORMATION

The participants in this study tried continuously to establish communication with their non-speaking children and young adults with CPMD. The mutual relations they attained relied on the daily use of nonverbal communications⁴, yet they were not aware of communicative musicality as a theory. During these interviews, more awareness and knowledge were developed and the parents could see how the use of communicative musicality and of music were pushing their families away from disability and hardship towards a different plane, where more equal, fluent and playful relations were afforded. Transformation was attained daily with the natural help of communicative musicality and music.

Music is performed at the service of change in many cultures, old and new (Wigram, Pedersen, & Bonde, 2002). Sekeles described some tribal musical rites from the Amazon, Madagascar, Moroccan Atlas and elsewhere. These rites were meant to transform body sensations and moods, and are reported as permanently healing various physical and emotional ailments (Sekeles, 1996). Music's

⁴ As portrayed in the theory of communicative musicality (Malloch, 1999; Malloch & Trevarthen, 2009).

independent powers of healing are controversial in music therapy (Aigen, 2014). Aigen (2007), as well as Tsiris (2008), support the thought that the art of music itself may afford the client's transformative experiences. Can music actually lead to change without the mediation of a shaman, priest or therapist? DeNora (2000) has suggested that even non-professional musicking can afford experiences of wholeness, self-acceptance and wellbeing. Flow – understood as optimal experience affording wellbeing and personal growth – is reported by some research participants describing their moments of deep engagement with music (Csikzentmihalyi, 1990). Silverman and Baker (2016) captured flow as a mechanism of change in general, and specifically in music therapy. These authors, based on a wide literature review, illustrated the power of musicking to increase the engagement and the sense of wellbeing and meaningfulness in various target groups. Moreover, musicking was found to induce flow bi-directionally, i.e., in both the clients and therapists. The participants in our study also described positive processes occurring while nonverbal communication and music were utilised with their children with disability. We suggest that both modalities based on the intact proto-musicality of the individuals with CPMD transformed their families' existence by affording them context, meaning and flow. The analysis of the research interviews underlines a few possible causes of the transformative effect of communicative musicality and of musicking on the families: the enhancement of coherency and order in their lives; the meaningful routines and relations established; and the ability to treat the individuals with cerebral palsy as equal partners. Music's joyful influence on these family members is also considered here. All the above causes are discussed in more detail below.

Coherence and order

All the research participants described their continuous path of seeking communication with their children and young adults with CPMD. Words could not serve this cause, and both parties' communicative musicality was their main meaning-maker. Gradual adjustment and attunement were described in this respect. The parents and children with cerebral palsy achieved highly synchronised nonverbal communications that improved their sense of coherence and order together. The state of coherence must not be undervalued, as it may serve as the baseline for uplifting, transformative experiences.

'Flow', the "optimal state of inner experience" described by Csikzentmihalyi (1990, p. 6), a positive psychologist, "requires order in consciousness". Communicative musicality is indeed about order: synchrony, turn-taking or carefully-constructed, recurring sequences are some of its building blocks (Malloch & Trevarthen, 2009). The nonverbal communicative approaches were gradually propelling these families' relations from trauma and chaos towards more orderly feelings and behaviours. The parents pointed directly at communication as the factor that changed their moods, improved the quality of relations, and afforded peak experiences, or, flow:

My husband makes all sorts of noises Roni likes. He does this sudden 'ATCHU!' and all kinds of silly voices, and Roni – she melts! She faints! You can't guess what happens here! What ecstasy, what rolling laughter – she simply cannot stop! (Roni's mother)

The use of music – singing, for instance – induced similar results:

When Tohar was a baby, bath was a time of joy. It's difficult for me to remember this time in our lives...only doctors, surgery, hospitals... Bathing her and singing always let me feel some serenity... It was good for her as well. (Tohar's mother)

Meaningful living

According to Maslow (1970), as people meet their basic needs, higher awareness can be achieved, characterised by "serenity, understanding, nobility, etc." (p. 99), as well as "loyalty, friendliness, and civic consciousness" (p. 100). Once the participants' communications with their children improved, the families' stress and struggle gave way to increasingly secure and open-minded experiences. They were now able not only to comprehend their individuals with CPMD, but to love them, personify them, and consider them as meaningful partners. A notion also prevailed that these children's birth was not in vain; that it had extraordinary, perhaps mystical, causes that positively affected their families' beliefs, morality and behavioural codes. We will not ascribe the attainment of coherence, order or meaning to communicative musicality alone, and yet, communicative musicality, as well as the moments of music the parents described, reflected a greater ability to view their children and young adults with CPMD as more equal family members. A strong family union was attained through musicking. These parents, struggling with their children's fragile health as well as other family concerns, saw their common music as uplifting and uniting.

Participation and inclusion

During the third interviews, parents described their children's isolation caused by CPMD. Musical moments, however, were experienced differently: in music, the individuals with cerebral palsy were more coherent to all family members. Dancing, singing, smiling or vocalising were everybody's appropriate responses to music, including the children and young adults with CPMD; here, nonverbal behaviours were quite acceptable and understood. Frequent use of music at home improved participation and inclusion within these families. "In music" exclaimed Noa's mother, "she is just as one of us!"

Some parents described their own lives as limited to their children's care; most of them did not develop careers and were less active socially due to the heavy burden of caregiving. The children's involvement with music afforded these parents the opportunity to take part in a cultural activity and reconnect to their surrounding social circles. In musical events they felt more welcome with their children with cerebral palsy. Csikszentmihalyi described large musical events as causing their audiences to lose the sense of individuality in favour of "'collective effervescence' or the sense that one belongs to a group with concrete, real existence" (Csikszentmihalyi, 1990, p. 110). Ansdell and DeNora (2016) described music as people's 'pathway' from social segregation towards participation. They saw music as 'bridging' between people of different classes and roles in communities. Music transformed these families' experiences from separation to equal participation and acceptance in their close environments.

Towards self-realisation

In the mornings everybody goes to work, school, and I do my house chores. This is the time for me to turn the music on and play it loudly; I've got an enormous playlist of songs! (Roni's mother)

Two main approaches to parenting were encountered in our study: either one parent gave up her mature way of living to initiate a fully-symbiotic unit with the individual with CPMD or, when both parents insisted on having their own adult lives, hired care was taken, and thus, parents felt, less mediation was given to their children. Both mechanisms – symbiotic-existence or separation – were experienced as taking their toll either on the parents or their children. However, the frequent use of music in everyday life allowed the participants to experience more self-realisation and connection with their proper age-group, with no sense of neglect towards their children. In music, each family member had more freedom of choice, and their own separate identities. "Listening to, performing and talking about music is not as much a reflection of identity as a way of performing the sense of ourselves. Our identity" (Ruud, 2009, p. 3). The parents' lived experience was similar: with music, they could form their own spaces within hectic daily schedules that required low use of precious resources of time and money. Tohar's mother described:

I always listen to music when I'm in my car, driving alone somewhere. It's high-volume rock music, you know, Deep Purple, and so – this is the music of my childhood.

Music, in DeNora's term (2013), assisted these parents in "refurnishing" or accommodating their lives so that some separation from their children with a disability was achieved, yet did not prevent them from bonding with, containing and caring closely for these individuals.

From suffering to joy

The children and young adults in this research experienced birth traumas and chronic health problems, as well as many sensitivities and functional limitations. However, they could enjoy music: it uplifted their moods and improved their quality of life. "Music," told Tohar's mother "is one basic thing you can use with a child. Over the years I have patiently taught my daughter how to hear music - just as I taught her how to eat." The effort this mother made to connect her child to music had to do, in our view, with another level of transcendence: from suffering to joy. That thought may seem simplistic, or very basic, yet it was not obvious to see that parents wished for their personified, included and beloved individuals with CPMD to also enjoy life despite their severe handicap and poor health. "Happiness," stated Csikszentmihalyi (1990, p. 2), "is a condition that must be prepared for, cultivated, and defended." Cultivating happiness meant, in these parents' lives, turning their backs on concerning reality and creating a more dynamic, enjoyable family experience. Music, so accessible presently, required only small effort to be utilised. It was described by all parents not only as encouraging positive changes, but also as affording their family an atmosphere shift, and moments of sheer joy.

Despite the participants' lack of awareness, they effectively used nonverbal communications – proto-communications and music – to improve their families' wellbeing: suffering was transformed to joy; practical and medical relations were transformed to personal and humane ones; chaotic experiences grew more meaningful due to the families' natural use of proto-musicality and everyday musicking at home.

CONCLUSION

In the light of our wider research (Roginsky, 2016; Roginsky & Elefant, in progress), we see a need to rethink our professional perspective on individuals with CPMD and their families. This study's results describe the natural appropriation of communicative musicality and music by the parents we interviewed. Music, we suggest, has transformative potential for these families. Enriching these families' daily lives with music and encouraging experiences of coherence, meaningfulness, joy, or the achievement of flow, are worthy of special attention while treating this population. Music therapy practice and research, accessible technologies, and parental experience can all prove highly useful. A more holistic, even spiritual sense of care may shift our point of view on individuals with CPMD, bringing more relevance and efficiency to our music-therapeutic effort.

REFERENCES

- Aigen, K. (2007). In defense of beauty: A role for the aesthetic in music therapy theory. Part I: The development of aesthetic theory in music therapy. *Nordic Journal of Music Therapy*, 16(2), 112-128.
- Aigen, K. (2014). *The study of music therapy: Current issues and concepts*. New York, NY: Routledge.
- Ammaniti, M., & Ferrari, P. (2013). Vitality affects in Daniel Stern's thinking: A psychological and neurobiological perspective. *Infant Mental Health Journal*, 34(5), 367-375.
- Alvin, J. (1961). Music therapy and the cerebral palsied child. *Developmental Medicine and Child Neurology*, 3(3), 255-262.
- Alvin, J. (1965). *Music for the handicapped child*. Oxford: Oxford University Press.
- Ansdell, G. (2014). *How music helps in music therapy and everyday life*. Farnham: Ashgate.
- Ansdell, G., & DeNora, T. (2016). *Musical pathways in recovery: Community music therapy and mental wellbeing*. London: Routledge.
- Beebe, B., & Steele, M. (2013). How does microanalysis of mother-infant communication inform maternal sensitivity and infant attachment? *Attachment and Human Development*, 15(5-6), 583-602.
- Brazelton, T. B., Koslowski, B., & Main, M. (1974). The origins of reciprocity: The early mother-infant interaction. In M. Lewis & L. A. Rosenblum, *The effect of the infant on its caregiver*. Oxford: Wiley-Interscience.
- Burkhard, A. (2013). A different life: Caring for an adolescent or young adult with severe cerebral palsy. *Journal of Paediatric Nursing*, 28, 357-363.
- Butterton, M. (2007). The therapeutic significance of communicative musicality in the practice of listening to music within psychotherapy and its psychobiological origins in early attachment experience. *Psyke & Logos*, 28(1), 310-332.
- Csikszentmihalyi, M. (1990). *Flow: the psychology of optimal experience*. New York, NY: Harper and Row.
- Cockerill, H., Elbourne D., Allen, E., Scrutton, D., Will, E., McNee, A., Fairhurst, C., & ... Baird, G. (2013). Speech, communication and use of augmentative communication in young people with cerebral palsy: The SH&PE population study. *Child Care Health and Development*, 40(2), 149-157.
- Corbin, J., & Morse, J. (2003). The unstructured interactive interview: Issues of reciprocity and risks when dealing with sensitive topics. *Qualitative Inquiry*, 9(3), 335-354.
- DeNora, T. (2000). *Music in everyday life*. Cambridge: Cambridge University Press.
- DeNora, T. (2010). Emotion as social emergence: Perspectives from music sociology. In P.N. Juslin & J.A. Sloboda (Eds.), *Handbook of music and emotion: Theory, research, applications* (pp. 159-183). Oxford: Oxford University Press.
- DeNora, T. (2013). *Music asylums: Wellbeing through music in everyday life*. London: Routledge.
- Denzin, N. K., & Lincoln, Y. S. (2011). *The Sage handbook of qualitative research* (4th ed.). Thousand Oaks, CA: Sage.
- Gilboa, A., & Roginsky, E. (2010). Examining the dyadic music therapy treatment (DUET): The case of a CP child and his mother. *Nordic Journal of Music Therapy*, 19(2), 103-132.
- Hart, T. (2000). Transformation as process and paradox. *The Journal of Transpersonal Psychology*, 32(2), 157-164.
- Kvale, S., & Brinkmann, S. (2009). *InterViews: Learning the craft of research interviewing* (2nd ed.). Thousand Oaks, CA: Sage.
- Linge, D. E. (2004). *Philosophical hermeneutics* (2nd ed.). Berkeley: University of California Press.
- MacDonald, R.A.R., (2013). Music, health, and well-being: A review. *International Journal of Qualitative Studies in Health and Wellbeing*, 8(10).

- Mahoney, J. (2016). Current practices in Nordoff Robbins Music Therapy (NRMT). In D. Keith (Ed.). *Qualitative inquiries in music therapy: A monograph series*. Gilsum, NH: Barcelona Publishers. Retrieved from: https://www.barcelonapublishers.com/resources/QIMT11/Mahoney_NRMT_Practice.pdf
- Malloch, S. (1999). Mothers and infants and communicative musicality. *Musicae Scientiae*, 3(1), 29-57.
- Malloch, S., & Trevarthen, C. (2009). *Communicative musicality: Exploring the basis of human companionship*. Oxford: Oxford University Press.
- Maslow, A.H. (1970). *Motivation and personality* (2nd ed.). New York, NY: Harper & Row.
- Marrades-Caballero, E., Santonja-Medina, C.S., Sanz-Mengibar, J.M., & Santonja-Medina, F. (2018). Neurologic music therapy in upper-limb rehabilitation in children with severe bilateral cerebral palsy: A randomized controlled trial. *European Journal of Physical and Rehabilitation Medicine*, 54(6), 866-872.
- McFerran, K.S., & Shoemark, H. (2013). How musical engagement promotes well-being in education contexts: The case of a young man with profound and multiple disabilities. *International Journal of Qualitative Studies in Health and Well-being*, 8(10).
- Meltzoff, A.N. (2007). 'Like me': A foundation for social cognition. *Developmental Science*, 10(1), 126-134.
- Miller, F., & Bachrach, S.J. (2007). *Cerebral palsy: A complete guide for caregiving*. Baltimore: Johns Hopkins Press.
- Nami, A. (2017). *The effects of music therapy on movement and vocalization in adult male with cerebral palsy: A case study and treatment plan* [Kindle edition]. Retrieved from www.amazon.com
- Nordoff Robbins (2008, August 6). Nordoff-Robbins Music Therapy Video Portrait (Part 1). [Video file]. Retrieved from: <https://www.youtube.com/watch?v=CuAjiU7RBg>
- Nordoff Robbins (2016, March 16). *Flynn's story*. [Video file]. Retrieved from: <https://www.youtube.com/watch?v=bqC8o6PFaEM&feature=youtu.be>
- Nordoff, P., & Robbins, C. (2007). *Creative music therapy: A guide to clinical musicianship* (2nd ed.). Gilsum, NH: Barcelona Publishers.
- Oskoui, M., Coutinho F., Dykeman, J., Jette, N., & Pringsheim, T. (2013). An update on the prevalence of cerebral palsy: A systematic review and meta-analysis. *Developmental Medicine & Child Neurology*, 55(6), 509-519.
- Papoušek, H., & Papoušek, M. (1992). Fragile aspects of early social integration. In L. Mooray & J. Cooper (Eds.), *Postpartum depression and child development* (pp. 35-53). New York, NY: Guilford Press.
- Papoušek, M., & von Hofacker, N. (1998). Persistent crying in early infancy: A non-trivial condition of risk for the developing mother-infant relationship. *Child: Care, Health and Development*, 24(5), 395-424.
- Parkes, J., Caravale, B., Marcelli, M., Francesco, F., & Colver, A. (2011). Parenting stress and children with cerebral palsy: A European cross-sectional survey. *Developmental Medicine and Child Neurology*, 53(9), 815-821.
- Ribeiro, M.F., Vandenbergh, L., Prudente, C.O., Vila, V.D., & Porto, C.C. (2016). Cerebral palsy: How the child's age and severity of impairment affect the mother's stress and coping strategies. *Ciência & Saúde Coletiva*, 21(10), 3203-3212.
- Roginsky, E. (2016). *Silent sounding: Communication and musicality in young individuals with profound CP and their parents*. Unpublished Doctoral Dissertation, University of Haifa, Israel.
- Roginsky, E. & Elefant, C. (in progress). Silent sounding: Parent's everyday use of musicality and music with their children with cerebral palsy and multiple disabilities.
- Rosenbaum, P., Paneth, N., Leviton, A., Goldstein, M., Bax, M., Damiano, D., Dan, B., & Jacobsson B. (2007). A report: The definition and classification of cerebral palsy. *Developmental Medicine and Child Neurology*, 49(SUPPL.109), 8-14.
- Ruud, E. (2009). Music and identity. *Nordic Journal of Music Therapy*, 6(1), 3-13.
- Seidman, I. (2006). *Interviewing as qualitative research: A guide for researchers in education and the social sciences*. New York, NY: Columbia University.
- Sekeles, C. (1996). *Music: Motion and emotion: The developmental-integrative model in music therapy*. St. Louis, MI: MMB Music.
- Sliberman, M.J., & Baker, F.A. (2018). Flow as a mechanism for change in music therapy: Applications to clinical practice. *Approaches*, 10(1), 2459-3338.
- Smith, J.A., Flower, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. London: Sage.
- Stern, D. (2010). *Forms of vitality: Exploring dynamic experience in psychology, the arts, psychotherapy, and development*. Oxford: Oxford Press.
- Thaut, M.H., Peterson, D.A., & McIntosh, G.C. (2006). Temporal entrainment of cognitive functions: Musical mnemonics induce brain plasticity and oscillatory synchrony in neural networks underlying memory. *Annals of N. Y. Academy of Sciences*, 1060, 243-254.
- Thaut, M.H., McIntosh, G.C., & Hoemberg, V. (2015). Neurobiological foundations of neurologic music therapy: Rhythmic entrainment and the motor system. *Frontiers in Psychology*, 5, 1185.
- Thompson, G., & McFerran, K.S. (2015). Music therapy with young people who have profound intellectual and developmental disability: Four case studies exploring communication and engagement within musical interactions. *Journal of Intellectual & Developmental Disability*, 40(1), 1-11.
- Trevarthen, C. (2015). Communicative musicality or stories of truth and beauty in the sound of moving. *Signata: Annals of Semiotics*, 6(3), 165-194.
- Tsiris, G. (2008). Aesthetic experience and transformation in music therapy: A critical essay. *Voices: A World Forum for Music Therapy*, 8(3). Retrieved from <https://voices.no/index.php/voices/article/view/1768>
- Whittingham, K., Wee, D., Sanders, M. R., & Boyd, R. (2013). Predictors of psychological adjustment, experienced parenting burden and chronic sorrow symptoms in parents of children with cerebral palsy. *Child: Care, Health and Development*, 39(3), 366-373.
- Wigram, T., Pedersen, N., & Bonde, L.O. (2002). *A comprehensive guide to music therapy: Theory, clinical practice, research and training*. London: Jessica Kingsley Publishers.

Επικοινωνιακή μουσικότητα, μουσική και μεταμόρφωση στις ζωές των γονέων και των παιδιών τους με εγκεφαλική παράλυση και πολλαπλές αναπηρίες

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ΠΕΡΙΛΗΨΗ

Οι γεννήσεις παιδιών με εγκεφαλική παράλυση και πολλαπλές αναπηρίες αποτελούν δοκιμασία για την ευεξία των οικογενειών τους. Αυτό το άρθρο, το οποίο βασίζεται σε ένα θέμα που προέκυψε από μια έρευνα βασισμένη σε συνεντεύξεις, υποδηλώνει ότι η επικοινωνιακή μουσικότητα και η καθημερινή χρήση της μουσικής μεταμορφώνουν τις εμπειρίες αυτών των οικογενειών. Τα ερευνητικά ερωτήματα αποσκοπούσαν στη διερεύνηση της μουσικότητας των ατόμων με εγκεφαλική παράλυση και της χρήσης της μουσικής εντός των οικογενειών τους. Στη μελέτη αυτή συμμετείχαν έξι γονείς ατόμων με εγκεφαλική παράλυση και πολλαπλές αναπηρίες. Τα δεδομένα συγκεντρώθηκαν μέσω μιας σειράς τριών συνεντεύξεων με κάθε συμμετέχοντα, οι οποίες εμπεριείχαν και την προβολή αυτοσχέδιων βίντεο που καταγράφουν στιγμές από τη ζωή στο σπίτι. Οι μεταγραφές των συνεντεύξεων αναλύθηκαν με ερμηνευτική φαινομενολογική ανάλυση και την εμπειρικά θεμελιωμένη θεωρία [grounded theory]. Αρχικά δημιουργήθηκαν τρεις βασικές θεματικές ενότητες (και παρουσιάστηκαν σε άλλη δημοσίευση). Η θεματική της «μεταμόρφωσης» είναι μια τέταρτη θεματική που προέκυψε από μια μεταγενέστερη ανάλυση των ερευνητικών συνεντεύξεων. Η θεματική αυτή παρουσιάζεται εδώ μέσα από τις φωνές των γονέων καθώς και από τις ερμηνείες των ερευνητών. Επίσης, συζητούνται οι θεωρητικές και ερευνητικές προοπτικές που σχετίζονται με την επικοινωνιακή μουσικότητα, την καθημερινή μουσικοτροπία [musicking] και την ευεξία. Προτείνουμε ότι τόσο η εντατική χρήση μη λεκτικών επικοινωνιακών προσεγγίσεων από τις οικογένειες όσο και η χρήση της μουσικής μεταμόρφωσαν τις εμπειρίες τους: μεταμόρφωσαν τη διάθεσή τους, τη συμμετοχή τους και τα νοήματα που σχετίζονται με τη συλλογική τους ζωή.

ΛΕΞΕΙΣ ΚΛΕΙΔΙΑ

εγκεφαλική παράλυση, πολλαπλές αναπηρίες, επικοινωνιακή μουσικότητα, μουσική, μεταμόρφωση, ευεξία