(2026). *New Zealand Journal of Music Therapy,* 24.

Establishing a Music Therapy Programme in a Specialist Children's Palliative Care Service in Aotearoa, New Zealand: Benefits and Challenges

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Keywords

Music therapy; paediatric palliative care; programme development; integrative care; music therapy programme report

Citation

Jeong, A. & Aburn, G. (2026). Establishing a music therapy programme in a specialist children's palliative care service in Aotearoa, New Zealand: Benefits and challenges. *New Zealand Journal of Music Therapy, 24*. https://doi.org/10.66180/CGGA5375

Review

This article was independently reviewed by two anonymous peer reviewers.

Abstract

This paper outlines the development and delivery of a philanthropically funded music therapy programme within a specialist paediatric palliative care (PPC) service in Aotearoa, New Zealand. Developed in partnership with a music therapy centre, the initiative sought to address needs of children with serious illness and their whānau (family), especially those experiencing medical fragility, social isolation, and limited access to therapeutic services. The programme, delivered predominantly in the home environment, utilised both in-person and telehealth modalities and was guided by carefully defined referral criteria to ensure equitable access within a limited service scope. Over nearly five years, music therapy supported 20 children and their families, offering benefits across multiple domains; emotional wellbeing, pain and symptom management, quality of life, and family connection. Despite these outcomes, the programme faced systemic challenges, including limited continuity, scheduling constraints, and interdisciplinary communication gaps, compounded by the absence of government funding. The findings underscore the value of embedding music therapy into standard PPC services. A formal partnership model is recommended as an interim approach, alongside further research to evaluate the lived experiences of children and whānau, and to further examine the clinical efficacy of music therapy within the PPC context in Aotearoa.

Paediatric Palliative Care (PPC) is an approach to care that seeks to improve the quality of life of children with serious illness and their whānau (family, including extended family), through the identification and assessment of suffering and treatment of distressing symptoms. Symptoms may include physical, psychological and spiritual distress (WHO, 2018). In Aotearoa New Zealand, PPC is informed by the well-recognised Māori model of health and wellbeing: Te Whare Tapa Whā. This model uses a whare (house) to symbolise oranga (wellbeing) acknowledging that care must address taha tinana (physical wellbeing), taha wairua (spiritual wellbeing), taha hinengāro (mental and emotional wellbeing) and taha whānau (family and social wellbeing), all in the context of the whenua (land and environment) in which the child and whānau are being cared for and reside (Durie, 1985).

Specialist PPC in Aotearoa has been recognised since the late 1990s, being one of the early pioneering services in PPC internationally. Despite significant advocacy within the country, there has been little priority afforded to the development of PPC services for this group of vulnerable children (Aburn et al., 2024). As a result, there is only one government funded specialist multi-disciplinary children's palliative care service in Aotearoa.

The service cares for approximately 50-60 children with serious illness each year. This includes whānau carrying a pēpi (baby) who is expected to die in utero or early in the neonatal period, children aged 0-15 years, and older adolescents who are in the process of transitioning to adult palliative care services (16-18 years). Approximately 80% of these children have a non-cancer diagnosis, with the majority of these children having serious illness with medical fragility and complex neurodisability (e.g. severe cerebral palsy, hypoxic brain injuries, neurodegenerative and neuromuscular conditions). Many are non-speaking and experience challenges with communication, temperature regulation, breathing and comfort. The other 20% of children have a cancer diagnosis, with approximately 50% of this group having a brain tumour resulting in similar challenges to children with neurodisability (Aburn et al., 2024).

Music therapy has been recognised as an integral component of quality PPC for children with serious illness (Duda, 2013; Kammin et al., 2024). Despite robust evidence for the use of music therapy in enhancing wellbeing for children and whānau, funding from the Ministry of Health to imbed music therapy within the multi-disciplinary PPC service is not yet in place. Music therapy is not yet recognised or funded as a core component of PPC in Aotearoa.

This report explores the establishment of a music therapy programme using philanthropic funding to support children cared for by a specialist children's palliative care service in a tertiary children's hospital in Aotearoa, in partnership with a music therapy centre.

Developing a New Music Therapy Programme in a Paediatric Palliative Care Service

Impetus for the service

Clinicians working in the specialist children's palliative care service in Aotearoa were aware of the integration of music therapy in PPC services internationally and had seen the benefits of this therapeutic support for children with serious illness and their whānau displayed at international conferences. Concurrent with this growing

awareness of the value of music therapy, a partnership programme was in development with the hospital play specialist service and a music therapy centre. Unfortunately, the funding and focus of the play specialist programme was only for children who were inpatients at the hospital. This meant children receiving palliative care in the community were unable to receive music therapy despite recognition that these children may benefit from it. Health professionals have identified that children receiving care in the community experience social isolation and challenging symptoms, and whānau can struggle to care for a medically fragile child at home. (Constantinou, et al., 2023; PaPCANZ, 2023; Winger et al., 2020). To ensure children in the community were able to access support, a proposal was developed and philanthropic funding sought for a music therapist to support children receiving PPC at home, one day per week.

Referral Criteria for PPC Community Music Therapy

Music therapy was limited to eight hours per week of therapist time for children receiving PPC in the community. Therefore, referral criteria were developed to ensure equitable access to music therapy support and the greatest benefit for the most children. Home visits were prioritised because of the vulnerability and fragility of the patient population. Delivering music therapy in the home environment offers significant therapeutic and relational benefits (Steinhardt et al., 2021). Such an approach enhances therapeutic engagement, reduces the likelihood of sessions being missed due to travel barriers and acute illness, and often fosters more authentic interactions than in clinical settings (Steinhardt et al., 2021). Home-based care also aligns with family preferences for maintaining a sense of normalcy during challenging times (Klinck et al., 2021). Many families value receiving care in familiar settings (McKinlay et al., 2021; Overå, 2023). Importantly, the home-based model respects children's and whānau choices regarding end-of-life care, supporting dignity and autonomy (Aburn et al., 2024; Pinto et al., 2024). Although sessions occurred in the home, the music therapy offered maintained the clinical rigour and ethical standards of hospital-based care (Knott & Block, 2020; Steinhardt et al., 2021).

To manage the challenge of delivering a service across the Auckland region, which spans over 1,000 square kilometres and includes a dispersed population, a decision was made to group children by location so the therapist could see them locally on a fortnightly basis. This approach enabled children to receive therapy over an extended period, despite the less frequent, fortnightly visits. While this model had the potential to affect the pace of relationship formation, the consistency of structured, ongoing contact fostered trust that support would continue, and ensured that progress toward goals remained steady and continuous over time.

The following referral criteria were developed:

- Child and whānau already receiving support for specialist PPC service
- Child and whānau experiencing isolation due to medical fragility and illness
- Child unable to access music therapy through other means (e.g. school, ACC, Oranga Tamariki – Ministry for Children)
- Child unable to attend day care or school due to medical fragility and illness
- Child and whānau willingness to engage with the music therapy programme
- Clinicians recognising an unmet need that could be addressed through music therapy interventions

To maximise clinicians' awareness of what might be achieved through music therapy, there were several initial discussions between the clinical director and music therapist to establish open lines of communication and awareness of the role music therapy could play in caring for the child and whānau.

Service Delivery

Since the inception of the programme, 20 children and their whānau have received the support of a music therapist in their home. This included nine children living with a neurodisability, four children with cancer and seven children with another form of serious illness. Many of the children had multiple and complex medical needs. Most children exhibited restricted movement due to limited energy reserves, fatigue and breathlessness. The use of feeding tubes and respiratory support (including invasive ventilation and central lines) further constrained the freedom of their activity. While many spent most of their time in bed or in a chair, their capacity for play was never compromised. This is because their creativity was not limited by their physical ability, but experienced through their ears to listen, eyes to see, heart to feel and mind to experience. Music therapy provided opportunities for emotional, musical, cognitive, and social engagement, enabling children to experience connection, expression, communication, discovery, and play.

Music Therapy Methods

Incorporating "receptive," "creative," "recreative" and "combined" music therapy methods made a stimulating and safe musical milieu for the children (Clements-Cortés, 2016, p. 126). Some interventions were delivered directly with the patients through singing, listening and playing instruments, along with the use of props, toys, and other objects to support the children's auditory, sensory, visual and kinaesthetic engagement. Multisensory experiences included gently swaying children on the bed or bouncing them on the couch to action songs, as well as projecting background effects with light projectors to accompany songs about space, sky, and water. At other times, activities focused on the family or the atmosphere in the room, to indirectly enhance the children's experience of the here-and-now. Following the child's lead, interests and strengths facilitated deeper exploration, providing opportunities they might not otherwise encounter. For instance, music interventions supported: reflection on life; exploration of self; emotionally safe risk-taking (through composing legacy songs to share with families or on public music forums); imaginative storytelling set to dramatised music; performing original compositions for families; and processing unresolved experiences such as trauma or broken friendships. However, these approaches were challenged during the Covid-19 lockdown; sessions needed to move online.

Telehealth Therapy

Music therapy was adapted to protect children in the early establishment of the programme hit by the COVID-19 pandemic. During this time, whānau were clear that they wanted therapy sessions to continue, and they were open to this occurring via telehealth. This reflected other therapeutic support occurring within PPC both in Aotearoa and internationally (Ebneter et al., 2022) and in other music therapy settings (Talmage et al., 2020). Although further training in digital competencies remains essential for clinicians, the benefits of virtual care - accessibility, flexibility, and autonomy - often outweigh its limitations (Keenan et al., 2021).

Although initial uncertainty existed regarding the efficacy of delivering music therapy online, emerging evidence affirmed telehealth's capacity to offer person-centred, ethical care through attention to digital non-verbal communication, such as tone of voice, facial expressions, and virtual proximity (Ebneter et al., 2022). Within this context, the digitalised environment functioned as a novel and stimulating 'meta' space in which the child could participate beyond the confines of home or hospital, enabling new experiences, connection and meaningful engagement despite physical separation. Virtual sessions consequently generated positive outcomes, with the sense of novelty and renewed agency supporting children in exploring experiences in interactive and motivating ways. At the same time, certain opportunities were unavoidably compromised, including shared tactile experiences such as passing instruments or hand-tapping; movement-based interventions like light bouncing and swaying; synchronous improvisation; and the ability to provide clear musical sounds and guidance in instrumental technique.

Online music therapy was provided via Zoom, with the option of pre-recorded sessions made available through a private YouTube channel or through direct download. While these virtual sessions were initially offered during the pandemic, they continued to be offered for whānau where this was their preference. In some cases, children demonstrated a preference for the interactive and visually stimulating features of digital sessions, which are not always replicable in live formats, such as replacing the background with a picture of a fantastical place or introducing a virtual cartoon character. The continuation of this model of service delivery reflects its adaptability and responsiveness to diverse child and whānau needs.

Therapeutic Goals and Benefits of the Programme

There were four key areas in the delivery of our music therapy programme which targeted challenges commonly experienced in PPC: whānau support; children's social needs; pain and symptom management; and wellbeing, enjoyment, and quality of life. To maintain confidentiality, these areas are described in general terms, with vignettes as illustrations. The vignettes are composite accounts, written to reflect the experiences and sentiments observed during the sessions while protecting patient anonymity.

Whānau Support

> *Mary's mother was initially hesitant to join the session. Yet, as the therapist's music created a fun and stimulating atmosphere, she felt a gentle invitation to participate. With a spark in her voice, she chimed, "ding-ding-ding!" guiding Mary's hands on the xylophone. Their playful energy intertwined with the therapist's music, and the mother's presence brought encouragement and reassurance. Each keystroke shared between Mary and her mother became an expression of love and connection, a small but meaningful song that carried their shared joy.*

Supporting whānau of children receiving palliative care is regarded as a central component of end-of-life care (PaPCANZ, 2023). Within the specialist PPC programme, parents experienced significant challenges, including difficulties securing carers, physical fatigue, and emotional distress. These challenges at times extended to siblings' wellbeing, as limited parental availability reduced opportunities for meaningful interaction with parents. The music therapy service therefore primarily

aimed to alleviate these physical and emotional burdens and to re-establish disrupted family connections.

Parents were frequently encouraged to actively participate in sessions through singing, playing instruments, or physically assisting their child's engagement. The therapist adopted a flexible facilitation style, at times leading sessions with varying energy levels and, at other times, alternating between guiding and supporting family-led interactions or maintaining a gentle musical presence in the background. This flexibility enabled families to engage in more intimate interactions with their child and supported parental autonomy (Barrett et al., 2022). In some sessions, the therapist facilitated whole-family music-making, allowing family members to participate on an equal level with the child for their own wellness and to share meaningful experiences.

Children receiving care often demonstrated heightened awareness and physiological responses, such as increased relaxation without pharmacological support. They also showed enhanced capacity for play, creativity, and improved mood, alongside increased opportunities to receive parental nurturing and care, which are integral to relationship formation. Observing improvements in their child had a direct positive impact on parents' sense of agency and self-worth and provided significant relief. Similarly, shared musical experiences with siblings supported sibling identity and connection. Older siblings, in particular, were able to express their role through making music for their younger sibling, while younger children received expressions of sibling affection through shared instrument play or serenading. Even in sessions without direct musical interaction, a shared sense of togetherness and exposure to the same therapeutic environment contributed to restoring aspects of family life as it once was, or as it might have been.

Following the death of a patient, follow-up visits were offered during which the therapist grieved alongside the family or provided music that their loved one had previously cherished. These musical experiences, embedding shared stories and memories of the life they had lived together, helped bridge past and present. Through conversation, listening to music, or viewing video recordings of therapy sessions, families were supported to revisit and honour their treasured moments.

Children's Social Needs

> *As the therapist sang Barney's 'I Love You' song, adapting the lyrics to "mummy loves you; you love mummy," Eddie, cuddled in his mother's arms, listened attentively and exclaimed, "You forget about daddy at work!" He then added, "Grandpa!" followed by "Grandma!" With the music reinforcing his love for his family, Eddie joyfully acknowledged each important person in his life, expressing affection and connection in ways that words alone might not have captured.*

Social interaction is vital to children's psychological and emotional wellbeing (PaPCANZ, 2023). Strong relationships, particularly within immediate family and therapeutic contexts, promote emotional awareness, empathy, resilience, and self-regulation (Benson & Haith, 2009). Accordingly, addressing children's social needs was considered essential to supporting their emotional and mental wellbeing.

Regular visits from the therapist enabled continuity of social engagement in the children's lives. While many patients were no longer able to attend their usual social activities, the therapist's consistent presence provided an ongoing source of social connection. At times, the therapist acted as a mediator between the child and the

outside world by introducing age-relevant trends through new songs, musical technologies, and music videos, which also served as prompts for discussion about contemporary social, political, and global issues. These approaches communicated to patients that their perspectives, interests, and participation in society remained relevant and valued.

Musical experiences involving family members and other healthcare professionals (when present), facilitated interpersonal connection; however, the therapeutic focus extended beyond shared music-making to the specific qualities of social interaction. These included opportunities for giving and receiving, sharing, being understood, acknowledged, heard, empowered, or appropriately challenged. Attention to these relational processes recognised that each individual occupied a distinct role within relationships and engaged socially in different ways.

Online musical platforms further provided some patients with opportunities for virtual social interaction. Selected music applications allowed users to share original compositions anonymously and to listen to others' work without disclosing personal identity. Through uploading electronically produced music, patients were able to engage in a shared online space and experience connection through non-verbal forms of social interaction. To ensure emotional safety within the specialist paediatric palliative care programme, interactive features such as commenting and rating were disabled, thereby reducing the risk of potential emotional harm arising from negative or absent responses.

Importantly, children do not only actively receive therapeutic support; they can also use music to communicate love, gratitude, and connection, for example, by singing to their parents, soothing a sibling with a lullaby, creating and gifting a personalised music video, or inviting everyone to participate. In doing so, children take on the roles of co-creators, leaders, helpers, and enablers. By engaging in these different societal roles, children experience a more enriching, balanced, and inclusive social dynamic and identity.

Pain and Symptom Management

Children who are receiving palliative care have serious illnesses with complex medical needs. Children are often receiving pharmacological treatments and support for a number of symptoms including pain and other distressing symptoms like breathlessness or seizures. However, music therapy at times produced observable outcomes in symptom and pain relief. Observable indicators included clients falling asleep during sessions, more regular breathing patterns, reduced facial tension, and decreased physical restlessness. While these observations cannot independently confirm pain reduction, they were consistent with increased comfort. In one case, a nurse reported that additional pain medication was not required following the session.

Patients' perception of the here-and-now was frequently altered through the playful and enjoyable atmosphere created within the therapeutic environment. Even when patients experienced ongoing physical discomfort, the lightened emotional tone in the room appeared to vicariously ease their experience, offering a momentary sense of relief and an alternative way of relating to their bodily sensations. It was recognised that the mood changes facilitated through therapy influenced patients' perception of both their present moment and their physical state.

Although music provided was not always overtly playful or joyful, contrasting musical approaches, such as soothing harp music or tranquil synthesiser textures, supported

relaxation. Observable changes included reduced facial grimacing, slowed breathing, and fewer physical signs of agitation. Many patients engaged in deep listening, and some subsequently fell asleep. When music yielded effects comparable to those of pain medication, it offered symptom relief without the associated pharmacological side effects. At times, relaxing music was combined with gentle lyrics that provided emotional reassurance, reinforcing a sense of being surrounded by love, care, and sources of comfort. These lyrical elements supported emotional ease and, on some occasions, enabled patients to transition from passive listening to active music-making after a period of relaxation.

Beyond symptom management, the presence of a therapist who was attentive to patients' needs and emotional states contributed an additional layer of relaxation and comfort. This relational aspect of care further supported patients' sense of safety and emotional wellbeing.

> *Julie's mother was hesitant - her daughter was far too unwell, she thought, too fragile even for the softest sounds. I offered to stay only as long as she could bear it, to leave at the first sign of discomfort. When I arrived, Julie couldn't even turn her head to acknowledge me. I sat quietly by her side and began to play - simple, familiar chords, gently woven with the occasional suspended note, like soft questions that always found comforting answers. I also used songs that reference familiar or fantastical places to provide imaginative escape by reframing the child's immediate experience of discomfort. The music floated through the room, not demanding, just there, offering warmth without asking anything in return. Slowly, her breathing shifted, more ease in the rhythm, less tension in her face. Her mother caught my eye, and gave me a thumbs-up - we had both seen it. As I turned to leave, Julie, slowly lifted her gaze to find me and gave me the quietest but most powerful "bye" I've ever received. From that day on, every time the pain returned, her mother would message: "Julie is looking forward to seeing you."*

Wellbeing, Enjoyment and Quality of Life

While music therapy offers accessible and meaningful forms of engagement, the therapeutic space also provides a safe and exploratory environment in which patients can identify and define what contributes to their own wellbeing, enjoyment, and quality of life. Through exposure to diverse musical approaches and opportunities to choose instruments and modes of engagement, patients were supported to articulate their preferences and participate in ways that were personally meaningful.

Experiencing a sense of control within sessions fostered agency, commitment, and responsibility; by leading the session, patients intuitively attuned to their own needs and were able to communicate what they sought from music therapy. Their choices included playing music with a parent, receiving affectionate physical contact accompanied by music, falling asleep while listening, vocalising sounds with the therapist, creating music videos as a legacy for family members, engaging with contemporary music to maintain a sense of identity, composing original music to share with a wider audience, and exploring reassurance around death in ways that incorporated familiar toys, foods, and people. Through these choices, patients actively shaped a therapeutic space that met their individual needs, which the therapist facilitated and held.

In many instances, during interventions they identified as both needed and desired, children responded in ways that aligned with their own expectations and inner intentions. Their responses ranged from excited clapping, vocalising, and dancing to moments of crying, emotional release, quiet contemplation, and even falling asleep - each reflecting what they needed in that moment. Music did not always enable overt forms of expression; at times, it functioned more subtly by allowing children to maintain a safe psychological distance, thereby supporting regulation and fostering a therapeutic space conducive to reflection and coping. In this sense, children actively shaped and guided the sessions in accordance with their internal needs. For younger children, or those with limited cognitive or verbal abilities, interventions were adapted to incorporate visual art, drama, props, and digital tools, thereby individualising meaningful therapeutic engagement.

Addressing wellbeing, enjoyment, and quality of life was therefore a creative process for the children, not simply because therapy was delivered through an art form, but because it involved the ongoing construction of meaning related to selfhood, needs, and desires. Music supported this philosophical and creative process enabling both concrete and abstract forms of expression through music-making. As a medium not bound to a single form, music allowed the therapeutic space to be shaped and reshaped in ways that reflected each child's evolving experience.

> *Daniel adored our Zoom sessions, watching the screen as if it were his favourite show. His mother joined in, providing live sensory input by using the same instruments she saw me play, making the experience more real for him. One day, she sent me a video of Daniel watching one of our recordings - despite feeling unwell, he lit up at the sound of my voice, clapping and smiling. "The only thing that cheers him up immediately is you," his mother told me.*

Discussion

This music therapy programme implemented within a specialist paediatric palliative care setting reflects a responsive and holistic approach, aiming to provide family support, address children's social needs, support pain and symptom management, and enhance overall wellbeing, enjoyment, and quality of life. Beyond facilitating experiences of normalcy despite the constraints of serious illness, the programme also created space for moments of profound expression, sacred joy, and deep connection. These experiences, shaped by the unique and often time-limited nature of paediatric palliative care, carried a particular intensity and meaning that may not emerge in other contexts; experiences that were both deeply human and significant to their particular circumstances.

Importantly, both the therapeutic goals and observed benefits of the programme are strongly grounded in existing literature, which highlights the efficacy of music therapy within paediatric palliative care contexts. The programme was intentionally informed by this evidence base to ensure that clinical practice remained rigorous while allowing flexibility to respond to individual needs. Furthermore, the outcomes observed in practice reinforce this body of knowledge, demonstrating how music therapy can be effectively translated into meaningful, real-world applications within specialist care settings.

The therapeutic processes outlined in this report should not be understood merely as theoretical constructs or aggregated findings, but as lived experiences. Viewing them

as expressions of situated evidence may help to maintain a practice-oriented perspective.

Whānau Support

Our programme identified the importance of whānau support and the literature highlights that providing psychological support for family members is a central component of PPC (Benini et al., 2022). It is recognised that parents and siblings often experience anticipatory grief, emotional exhaustion, and a sense of helplessness in the face of their child's progressive deterioration (Barrett et al., 2022). Music therapy offers tangible, lasting forms of support (O'Callaghan, 2013). For example, families may choose to record therapy sessions, recognising these moments as precious memories. These recordings may become transitional objects; comforting items that connect them to their child after death (Lindenfelser et al., 2008; Rodríguez-Rodríguez et al., 2023). The personalised videos that patients created in our music therapy sessions can help families to feel a psychological connection with their child after death.

Children's Social Needs

The music therapy programme offered a uniquely responsive and relational space in which these social dynamics could be preserved, explored, and deepened. As a non-verbal and paraverbal medium, music allows participation despite physical or communication barriers (Rees, 2005). Positive emotional experiences in music therapy can normalise children's responses to illness and emotional space and allows families to express themselves openly (Lindenfelser et al., 2008; 2012; Mottram & Rigney, 2020; Rodriguez-Rodriguez, 2023). Within this context, they can grieve, demonstrate love, and share gratitude; emotions that may be difficult to acknowledge elsewhere (Rees, 2005). Music therapy provides a milieu that is safe, emotionally accommodating, and developmentally appropriate, fostering meaningful emotional expression for both children and their families; the therapeutic space becomes a sanctuary for vulnerability, permitting families to cry, support each other, hold hands, or sing in rhythm, which are gestures of deep emotion (Jeong, 2016; Krout, 2003). Such moments of emotional expression and relational anchoring, help families come together as one again and navigate uncertainty with connection and tenderness.

It is important to acknowledge that not only do children actively receive therapeutic support; they are also empowered to communicate their love, gratitude and connection (Aasgaard, 2001; Rees, 2005; Whittall, 1991). In doing so, children take on the roles of co-creators, leaders, helpers, and entertainers. By engaging in these different societal roles, children experience a more enriching, balanced, and inclusive social dynamic.

Pain and Symptom Management

Managing pain and other distressing symptoms is a central component of PPC and can significantly impact a child's quality of life (Steinhauser et al., 2000). This was one of the key therapeutic goals of our programme. Children's pain is multidimensional; simultaneously experienced on sensory, emotional, and physical levels (McMahon et al., 2013). Music therapy experiences can address this full spectrum of needs.

Play, including musical play, is a developmentally appropriate strategy for children to express emotions, access coping mechanisms, cultivate resilience and experience

personal growth despite serious illness (Williams et al., 2014). Remarkably, children often retain an extraordinary capacity for joy, creativity, and engagement, sometimes surprising those around them (Mahoney, 2019; Aasgaard, 2001). The use of songs and play that incorporate linguistic and numeracy skills, as well as concepts such as colours, places, and body parts, contributed to children's continuing development.

Receptive music experiences, such as passive listening to calming melodies, offer support when active participation is not possible. Research has demonstrated measurable physiological effects in response to music. Music can alter pain perception by modulating emotional and sensory pathways (Dobek et al., 2014), elevate dopamine levels associated with pleasure and reward (Zatorre & Salimpoor, 2013), and disrupt the brain's pain processing circuits (Garza-Villarreal et al., 2014). While play provides emotional support and mental strategies that outweigh physical challenges by changing the perception of here and now, music also directly changes physiological markers.

These examples suggest that music therapy is well-suited to managing distress in PPC. Its therapeutic effects arise from modulating emotional responses, providing distraction, and facilitating biochemical changes; strategies that enhance the child's overall improvement of physical health (Klassen et al., 2008).

Wellbeing, Enjoyment and Quality of Life

As found in our programme, music therapy can make a substantive and unique contribution to improving the quality of life for children and their whānau. While the concept of quality of life remains inherently subjective and varies according to individual meaning (Fowlie & Berkeley, 1987; Nordenfelt, 1993), music therapy addresses many of its core domains. These include pain and symptom management (Dobek et al., 2014; Garza-Villarreal et al., 2014; Zatorre & Salimpoor, 2013; Delaney et al., 2023; Lindenfelser et al., 2012), opportunities for play and enjoyment (Lindenfelser et al., 2012 Mottram & Rigney, 2020), and the facilitation of spiritual experiences such as finding meaning and purpose of life, or having transcendental experiences that help them rise above difficulties (Rees, 2005; Rodriguez-Rodriguez et al., 2023). Importantly, quality of life may be supported and enhanced through music therapy, notwithstanding the progression of health deterioration (Hilliard, 2003; Wei, 2014).

Challenges

Delivering music therapy as a visiting contractor within PPC posed a number of systemic and logistical challenges. These related to service continuity, equity of access, and team-based care coordination.

The programme was community-based and sessions took place in the home. Travel was an unavoidable component, consequently reducing flexibility and the time available for direct therapeutic engagement. The fixed service delivery schedule, restricted to a single day each week, frequently limited the capacity to provide appointments that aligned with both the child's optimal functioning and family availability. This created scheduling conflicts and may have compromised the quality and therapeutic potential of the intervention (Porter et al., 2017). Session cancellations, whether arising from acute medical deterioration or complex family circumstances, could not be rescheduled, thereby further compromising the continuity of care. Despite

clear therapeutic benefits, the duration of music therapy was often curtailed prematurely, as the presence of a waiting list necessitated that each patient received a fixed allocation of therapy time before the service was made available to the next child.

Operating outside the core hospital-based team also contributed to a sense of professional isolation for the music therapist. Communication gaps affected the timeliness and quality of care, as important updates about the child's condition or family circumstances were not always able to be conveyed promptly. From anecdotal evidence, these challenges are not unfamiliar to other music therapists working in PPC settings. Collectively, these challenges underscore the need for more integrated service models and communication pathways.

Future directions

Our music therapy service has demonstrated clear benefits for children receiving PPC. However, challenges in service delivery, equity, and access have limited the extent to which the service can be optimised. In Aotearoa, the absence of government funding for music therapy in PPC constrains both the number of hours therapists can directly provide care within the healthcare system and thus the overall quality of service patients receive. One significant opportunity to address this gap lies in integrating music therapy into the core multidisciplinary team within hospital-based care. Embedding the profession in this way would allow for greater flexibility in service delivery, increase the number of children able to be referred (including those experiencing acute distress or approaching the end of life) and strengthen interdisciplinary collaboration. Integration would also enable music therapists to participate in joint assessments and visits, contribute meaningfully to care planning, and receive appropriate peer support. Given these advantages, there is a strong case for government funding to support music therapy as a standard component of national PPC services in Aotearoa, thereby improving both the quality of care and patient wellbeing.

While advocacy for such funding is ongoing, in the interim, a formal partnership model is recommended. Under this approach, music therapists would remain contracted through specialist centres but participate actively in shared supervision, joint care planning, and regular team meetings. Whether embedded as core team members or engaged as externally-contracted specialists, more integrated service models have the potential to maximise clinical impact and, ultimately, improve the consistency and quality of care for children receiving palliative care and their whānau.

Alongside the development of services, further research is required to explore the perspectives of children and whānau on the role of music therapy in PPC within Aotearoa. Such research should also investigate the potential contributions of music therapy to the Māori health model Te Whare Tapa Whā, examining its effectiveness in addressing this holistic health model unique to Aotearoa New Zealand.

Conclusion

It is important to recognise the interventions outlined in the article may be understood not merely as theoretical constructs, but as approaches that practitioners can meaningfully employ in response to the real-world needs as they originate from the

lived experiences of patients and families. Rather than seeing them solely as aggregated findings, but more as an expression of situated evidence may help to maintain a practice orientation grounded in the realities of patient care.

The establishment of a philanthropically funded music therapy service within a specialist paediatric palliative care service in Aotearoa highlighted its clear benefits for children and their whānau. Yet, operating as an adjunct service rather than an embedded element of core clinical practice revealed challenges. Moving forward, embedding music therapy within the PPC team, supported by government funding, would enhance flexibility, increase referral capacity, and improve collaborative care. In the interim, a formal partnership model could help bridge current gaps and strengthen integration. Further research is needed to support the development of this service to ensure culturally responsive, equitable palliative care of music therapy within PPC.

Acknowledgements

We gratefully acknowledge the generous support of Music Therapy New Zealand's McKenzie Hospice Fund, the Louisa and Patrick Emett Murphy Foundation, and the Hulijch Trust for their financial contributions to this programme. We also thank Alison Talmage for her valuable feedback.

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