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CASE REVIEW

Educational Therapy in Paediatric Palliative Care: A Case Study of a Child with Complex and Life-Limiting Condition

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ABSTRACT

Children with complex and life-limiting (CLLC) conditions require holistic care that supports not only symptom management but also their emotional, developmental, and relational well-being. Despite growing evidence on multidisciplinary approaches in pediatric palliative care (PPC), there is little focus in literature on specific role of educational therapy (EdTx). This paper explores how EdTx can contribute to dignity-centred palliative care through the case of a seven-year-old girl diagnosed with Mosaic Trisomy 13. Drawing on theories of emotional development and relational care, the case illustrates how educational therapy can enhance communication, agency, and legacy-building across home, school, and clinical settings. Educational therapists (ETs) are essential partners in co-creating meaning and preserving the identity of children with progressive decline in cognitive and physical functions. This case also offer practice-based insights into how educational therapy bridges psychosocial, developmental, and pedagogical dimensions of pediatric palliative care. The insights advocate for an integrative, relational approach that centres the child's presence, voice, and dignity throughout the palliative care journey.

Keywords: *Paediatric Palliative Care, Dignity-Centred Models of Care, Educational therapy, Legacy-building, Complex and Life-limiting Condition*

1. INTRODUCTION

Complex and life-limiting conditions (CLLC) refer to medically complex diagnoses that are often progressive in nature and have a substantial impact on a person's health, development, and overall quality of life (Kim et al., 2018; Bendle & Laddie, 2019). These conditions frequently affect multiple organ systems and require long-term, multidisciplinary care that extends across clinical and community settings.

CLLC encompass a broad spectrum of diagnoses, including neurological and neurodevelopmental disorders; genetic, metabolic and cardiopulmonary diseases; gastrointestinal and hepatic disorders; and immunological or haematological illnesses. Children with such diagnoses often require ongoing medical management alongside consistent therapeutic intervention.

Therapists working with children with CLLC must readily address emotional regulation, sensory integration, and the child's search for meaning as they begin to grapple with illness, health decline, and the reality of mortality. Research by McAfee et al. (2023) and McPoland et al. (2024) shows that even children as young as five possess the emotional insight and cognitive capacity to understand and respond to the concept of death and dying. While they may not always have the vocabulary to articulate their thoughts directly, their understanding often emerges through alternative forms of communication. Symbolic play, narrative expression and emotional cues are forms of non-verbal communication that align with their developmental stage. Far from being passive, children with CLLC actively seek meaning, express fears, and ask profound questions through emotionally driven and symbolic forms. This highlights the importance of developmentally appropriate, narrative-based interventions that allow children to explore their thoughts and emotions in safe and meaningful ways. Engaging them early with care not only offers therapeutic support but also respects the child's inner world during some of the most vulnerable moments of life.

Paediatric palliative care (PPC) is an integrated and comprehensive approach to care that encompasses physical, emotional, social, and spiritual elements for children with life-limiting or life-threatening conditions (Bendle & Laddie, 2019; Chia, 2025). It consists of complex symptom management, anticipatory guidance, advanced care planning, and end-of-life support (Bendle & Laddie, 2019). While healthcare and education systems use various terms such as complex chronic conditions (CCCs), chronic complex diseases (CCDs), and chronic childhood conditions to describe these needs, each term reflects a growing awareness of the unique challenges involved (Chia, 2025). In this paper, the term *complex and life-limiting conditions (*CLLC) is used to recognise the ongoing medical challenges these children face, as well as the possible impact on their life expectancy, development, and emotional well-being.

1.1 Prevalence and Public Health Trends

Medical professionals currently use the Paediatric Palliative Screening Scale (PaPaS) to assess and identify children with CLLCs for palliative care support (Simões et al., 2023). Using this tool, professionals can make timely and informed decisions about referrals and ensure that the child's medical and psychosocial needs are supported. Simões et al. (2023) emphasise that the primary goal of paediatric palliative care is to alleviate suffering and manage distressing symptoms of children with CLLC. Focusing on the care component will enhance the overall quality of life for both the child and their family.

Although CLLCs are increasingly recognised as public health concerns, there is still a lack of consistency in how they are defined and tracked across countries. In a large cohort study in the U.S. involving 1.9 million children, Leyenaar et al. (2022) reported that the prevalence of children with medical complexity ranged from approximately 0.67% to 11.4%, depending on the classification criteria and data sources used. When applying stricter definitions that required high health-care utilisation, the estimated prevalence was around 0.67% (roughly 67 per 10,000 children). Wisk and Sharma (2025) also observed a steady increase in these conditions, noting that nearly one in three children aged 5 to 17 now live with at least one chronic condition, most commonly involving neurodevelopment, respiratory health, metabolism or mental well-being. In Singapore, an advanced centralised health informatics infrastructure underpins national chronic disease surveillance and patient tracking. For example, the National Healthcare Group's Chronic Disease Management System (CDMS) currently holds data on 1.2 million patients with more than 100 chronic conditions, including diabetes, hypertension, chronic kidney disease, and coronary disease (Toh et al., 2019). The National Electronic Health Record (NEHR) complements this by enabling cross-institutional sharing of health data among public and private providers, thereby facilitating continuity of care across sectors (Singapore Ministry of Health, 2025) These data infrastructures play an essential role in helping health authorities plan services at a population level and coordinate more comprehensive, child-centred support for those living with chronic and life-limiting conditions.

Taken together, these international findings highlight the growing prevalence and complexity of complex and chronic childhood illnesses, as well as the corresponding need for integrated care models. Educational therapy (EdTx), when meaningfully integrated into paediatric palliative care, provides a vital avenue to meet the psychosocial, cognitive, and relational needs of these children in culturally attuned and developmentally appropriate ways.

The burden of CLLCs in children is increasingly being quantified using population health metrics such as Disability-Adjusted Life Years (DALYs). DALYs combine years of life lost due to premature mortality with years lived with disability (Murray, 1994; WHO, 2023). This measurement highlights both the medical consequences of illness and the psychosocial impact on daily functioning. Using such a metric reinforces the importance of non-pharmacological interventions such as EdTx, which helps to restore participation and autonomy in children with complex health needs (Cassini et al., 2018)

1.2. Reframing Educational Therapy in Paediatric Palliative Care

Educational Therapy (EdTx) is a *"treatment approach in which there is a delivery of adequate measures which are modelled to alleviate a psycho educational and/or psycho-behavioural condition"* for individuals (Chia & Camulli, 2018, p. 32). While the approach has been widely recognised to address cognitive and academic challenges, EdTx is also gaining popularity for its role in addressing psychosocial care for children with CLLC. Cai et al. (2023) emphasise that EdTx plays a pivotal role in promoting a child's overall well-being by creating continuity between clinical care and educational engagement. Chia (2025) also proposed that educational therapists (ETs) are uniquely positioned to complement paediatric palliative care by bridging cognitive, emotional, and relational support within clinical and educational systems. Their work emphasises preserving identity, facilitating meaning-making, and honouring family narratives" (Chia, 2025).

Mandala drawing is one of the meaningful approaches to supporting children with CLLC. This process invites focus and gentle engagement of the child's senses, making it particularly effective in fostering sustained attention and promoting emotional self-regulation. For children navigating the uncertainties of chronic illness, mandala drawing offers a non-verbal and culturally adaptable outlet through which they can process emotions, externalise distress, and regain a sense of psychological control. Within paediatric healthcare settings, mandala-based activities are increasingly recognised for their therapeutic value and their potential to enhance connections between children, caregivers, and therapists. Liu et al. (2020) found that both individual and group-based mandala activities led to measurable improvements in emotional stability and overall psychological well-being among hospitalised children.

The dignity-centred models of care complement the Mandala as they promote the therapeutic importance of preserving agency, fostering relational continuity, and facilitating legacy-making. Lin et al. (2024) and Cai et al. (2023) advocated for incorporating these principles into structured interventions that address the spiritual and existential needs of children nearing the end of life.

Educational stakeholders also play a critical role in extending therapeutic support for children with CLLC to the learning environment. By working closely with educational therapists (ETs), stakeholders such as teachers help to ensure that interventions are not only targeted and consistent but also responsive to the child's evolving medical, emotional, and developmental needs (Yusof, 2025). This alignment across home, school, and clinical settings enable a more holistic approach, where education becomes a stabilising force rather than a source of additional stress for such children. Bourke and Roper (2021) noted legacy-making rituals, peer circle discussions, and teacher capacity-building programs actively promote social connection and create safe spaces that recognise children with CLLC for their lived experiences, preferences, and contributions. Inclusive practices not only humanise the learning experience but also affirm the individuality and dignity of the child living with such conditions. It also fosters a compassionate and responsive peer culture.

Integrating therapeutic approaches into school settings also marks a significant departure from conventional models of teaching and learning. This approach reflects a more profound transformation in education, particularly in contexts including children with CLLC who are receiving paediatric palliative care. Children with chronic health issues often require support that goes beyond academic instruction to include emotional regulation, identity affirmation, legacy-building, and relationship-centred engagement. Working on such activities requires a re-imagination of educational priorities in the school system. Wang et al. (2024) highlighted that there is a need for transformative leadership in schools which respond to the evolving needs of children living with CLLC. Effective leaders in this context must advocate for pedagogical flexibility and foster a school culture rooted in equity, collaboration, and child-focused care practices. Despite ongoing progress, systemic challenges persist in providing adequate support for children with complex and life-limiting conditions. In particular, the lack of coherence across education policies continues to undermine the delivery of specialised support for them (Zhang & Deng, 2023). These challenges are evident when coordination between the health, education, and social service sectors is weak and fragmented. This fragmentation can create risks for children as they navigate multiple systems of care, especially during critical transitions between home, hospital, and school environments. In response, Xue (2024) advocated the need for systemic reform to ensure equitable access and continuity of care for children with complex and life-limiting conditions.

1.2.1 Adopting Culturally Responsive Practices

Recent research has offered valuable insight into how children, some as young as five years old, process experiences related to illness, spirituality, and the concept of death and dying. McPoland et al. (2023) observed that young children have the capability to understand complex themes, such as mortality. They are also able to express deeply personal and reflective thoughts about such themes. These findings highlight the need for relational-based approaches in paediatric palliative care.

Within both hospital intensive care units and home-based palliative settings, EdTx plays a vital role in bridging medical care with the emotional realities of family life. ETs support children and their families by introducing symbolic tools for shared expression, facilitating creative memory-making, and incorporating rituals that allow space for emotional processing. These practices help maintain the child's sense of identity, agency, and belonging—even in the face of uncertainty and health decline.

Studies (e.g., Cai et al., 2023; Lin et al., 2024; Iannello et al., 2022) in dignity-centred models propose embedding therapeutic care within the child's cultural and relational context. These studies demonstrate how structured family rituals, narrative interventions, and culturally grounded dignity therapies can preserve identity, facilitate meaning making, and strengthen relational continuity at the end of the life of the child. This model also encourages medical professionals, allied healthcare providers, and families to reflect on the principles that shape their practice, while embedding strategies that uphold the child's dignity and identity towards the end-of-life care.

Sensory integration continues to play a vital role in therapeutic interventions within paediatric palliative care. Children living with CLLC often experience heightened sensory processing that affects comfort and emotional stability. Schoth et al. (2022) found consistent differences in pain thresholds and tactile perception among children with chronic conditions, linking sensory modulation difficulties to distress and withdrawal. These insights support incorporating sensory-based strategies into the care routine to enhance regulation and well-being in therapy (Randell et al., 2022). ETs will find this use of sensory-based techniques helpful when dealing with intense moments, especially when children struggle to express distress through verbal or behavioural cues. In such moments, these techniques provide a sense of grounding and familiarity for these children, especially when they are adapted to the unique needs of each child.

Spirituality and cultural continuity also serve as critical protective factors for both children and families navigating complex and life-limiting conditions. Many families draw on familiar spiritual or cultural practices to make sense of difficult experiences and to sustain hope and connection. Research by Iannello et al. (2022) found that individuals who regularly participated in spiritual or religious practices demonstrated higher levels of psychosocial resilience. They are also more likely to follow their treatment and care plans. Similarly, Ghezelseflou (2023) reported that being a part of spiritual support systems improves the emotional well-being of individuals living with chronic health conditions. These findings reinforce the value of integrating cultural and spiritual dimensions into educational therapy. In practice, aligning therapeutic work with what is meaningful to the child and family helps bridge clinical goals with the lived realities of the child's identity and belief systems. (Boesch et al., 2013; Cai et al., 2023; Lin et al., 2024).

1.2.2 Integrative Frameworks and Therapeutic Design

Within paediatric palliative care, ETs assume an expanded role which involves helping children with emotional regulation, communication, symbolic expression, and narrative meaning-making. This approach is closely aligned with dignity-centred care frameworks that prioritise the child's agency and relational environment. By working across therapy, home, and school settings, ETs help ensure that care is not only developmentally appropriate but also emotionally resonant and culturally relevant. Sensory tools, such as weighted blankets, tactile books, and interactive lightboards, are increasingly used in therapeutic settings (Randell et al., 2022) and will be part of the ETs toolkit when working in paediatric palliative care.

ETs will also have to include elements such as family rituals, multilingual communication, and spiritual tradition to affirm the child’s sense of identity and nurture stronger emotional bonds within the family unit (Iannello et al., 2022; Ghezelseflou, 2023). These practices are central to honouring the lived experiences and cultural narratives of each child.

There is also an increase in mindfulness-based creative therapies such as music-assisted relaxation, mindful colouring, and guided art journaling in paediatric palliative care to encourage self-expression and help children manage anxiety (Campenni & Hartman, 2019; Liu et al., 2020). Among these, mandala drawing has emerged as a powerful tool for supporting emotional stability in hospitalised children (Liu et al., 2020). Campenni and Hartman (2019) also observed that these practices help lower anxiety levels and support mood regulation in children with limited verbal expression. Mandala art therapy provides a structured outlet through which children can express emotions, improve focus, and share insights into their worlds (Campenni & Hartman, 2019; Liu et al., 2020; Roquet & Sas, 2021）. Roquet and Sas (2021) also proposed integrating these creative tools with digital mindfulness platforms to optimise neuro-emotional regulation through creative engagement.

Given the complex interplay between medical fragility, cognitive development, emotional regulation, and familial dynamics, there is a need to define how EdTx can be adapted for children with CLLC. While much of paediatric palliative care centres on clinical management, EdTx complements this approach by supporting continuity of care, sustaining the child’s sense of identity, and fostering shared meaning through collaboration with the child and family.

Typically, ETs should notice the shift in learning priorities for children with CLLC by focusing on meaningfully constructed goals over future-oriented ones (Carstensen, 1992). With this understanding, ETs can offer developmentally appropriate, culturally grounded, targeted and evidence-based interventions that align with the dignity, autonomy, and psychological well-being of such children. By positioning EdTx alongside medical, psychosocial, and spiritual interventions, this paper aims to position its role in sustaining identity, affirming agency, and fostering meaning-making for children with complex and life-limiting conditions. The objectives of this paper are: (1) to demonstrate case-based analysis that supports communication when traditional language use may be limited, (2) to examine how targeted therapeutic strategies can facilitate emotional regulation across developmental and cultural contexts, and (3) to explore legacy-building practices that preserve continuity, memory, and relational bonds in children with CLLC.

The following vignette illustrates how this multi-modal approach guides ETs in planning support for a seven-year-old girl who has Trisomy 13 and navigating the complexities of a chronic and life-limiting health condition. Apart from learning and self-regulation, her therapy goals and plan sought to honour her emotional voice, sustain family connection, and co-create a legacy that reflected her spirit and identity.

1.3 Case Vignette: Amira Noor

Amira Noor[1], a seven-year-old girl, is diagnosed with Mosaic Trisomy-13, a rare chromosomal disorder characterised by significant neurodevelopmental impairment and reduced life expectancy. While children with full Trisomy-13 typically survive only a few months, those with mosaic variants may live into late childhood or early adolescence, though life-limiting complications are still anticipated. During Amira's early years, surgical correction of congenital heart defects and the timely introduction of anti-epileptic medication helped to stabilise her medical condition. However, over the past two years, she exhibited signs of progressive decline, including language regression, decreased physical stamina, and cognitive slowing.

Amira attended a government-funded special education school for children with complex medical needs. In school, her teachers observed a marked reduction in her verbal communication and withdrew from social activities at times. Whenever she is exposed to loud sounds and unfamiliar textures, she also exhibits heightened emotional reactivity. Her condition led to frequent absences due to fatigue and recurrent respiratory infections, which further disrupted her learning engagement and peer relationships.

The paediatric team conducted a multidisciplinary developmental assessment and confirmed a diagnosis of mild intellectual disability (Leiter-3 IQ approximately 55), along with delayed fine motor skills, auditory defensiveness, and tactile hypersensitivity. Despite these challenges, Amira shows notable areas of strength. Amira responded positively to music and was able to sustain visual attention during structured activities. She also engaged meaningfully in calm, familiar interactions throughout daily routines.

Amira's family, guided by their Islamic faith, placed substantial importance on spiritual readiness and emotional closeness during her care journey. They expressed a preference for therapeutic intervention that would support Amira's sense of autonomy and happiness in daily routines while also offering ways to create lasting memories for their family. In line with these values, Amira was referred for educational therapy as part of a coordinated palliative care plan involving her school, home, and medical team.

1.4. Individualised Educational Therapy Plan in Paediatric Palliative Care

To support Amira's needs within a paediatric palliative care context, her educational therapy plan will focus on several domains. These include cognitive abilities, emotional expression, sensory profile, and relational environment. The therapy plan will draw on evidence-based practices in paediatric palliative care, while remaining responsive to the progression of her medical condition and the realities of her limited prognosis.

The primary aim is to create meaningful, developmentally appropriate opportunities for engagement, communication, and emotional support. The intervention will balance structured educational tasks with therapeutic encounters that centre on comfort, agency, and connection. Informed by her sensory

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[1] *Note: This vignette is a hypothetical composite case developed based on the profile of a child in Singapore with similar medical and developmental characteristics. All personal identifiers have been removed following the Personal Data Protection Act 2012 (with Amendments in 2020)*

sensitivities and expressive challenges, the strategies will emphasise visual, tactile, and auditory modalities to scaffold learning and interaction.

1.4.1 Overall Therapy Goal

The ET will offer Amira consistent opportunities for meaningful participation, cognitive stimulation, and emotional security, within the context of her complex health condition, guided by the principles of palliative educational therapy.

1.4.2. Learning and Communication Support Strategies

Amira will benefit from a Total Communication Approach, which is a multi-modal form of augmentative alternative communication (AAC) strategy. Combining Picture Exchange Communication Systems (PECS), gestures, and verbal modelling, this approach will support Amira's expressive autonomy. Boesch et al. (2013) found that multi-modal AAC strategies improve social-communicative outcomes in minimally verbal children with developmental conditions. For Amira, therapists will model speech and gestures alongside visual symbols to encourage responses and reduce frustration associated with verbal regression.

The ET will also introduce tactile-based storytelling using textured books and interactive light-boards to build her language comprehension and word association skills. These tools are intended to activate Amira's visual and tactile processing channels, helping her focus and engage without overstimulating her auditory system. Structured play-based learning using cause-and-effect toys, musical mats, and symbolic dolls will be embedded into daily sessions to reinforce language, sequence recognition, and metaphorical thinking.

1.4.3 Emotional and Psychosocial Support Strategies

The ET will also incorporate cooperative mandala drawings into sessions with peers and family members. These shared experiences support emotional connection, reflection, and co-regulation through the symbolic use of colour, shape, and repetition (Liu et al., 2020). In addition, individual mandala colouring will serve as a grounding exercise to support Amira's emotional stability and sense of autonomy, enhancing mindfulness and emotional processing during periods of distress.

To encourage social connection, the educational therapist will collaborate with the classroom teacher to select one to two neurotypical peers who will be trained as “communication buddies” These peers will receive basic training through a structured Peer Inclusion Program, equipping them to assist Amira in navigating daily routines, engage in shared play, and model appropriate communication in both structured lessons and informal settings. This approach fosters mutual understanding, promotes inclusive peer relationships, and reduces the risk of social isolation for children with complex communication needs (Asmus et al., 2017).

Music elements will also be incorporated into therapy sessions twice a week, focusing on rhythm, vocalisation, and instrumental improvisation. Music, apart from art, has been shown to facilitate emotional expression, particularly in children with limited verbal capacity (Campenni & Hartman, 2019), and will be tailored to Amira's preferences for comfort and emotional safety.

Figure 1. A memory book featuring photographs of the child's favourite items, along with new objects introduced during therapy sessions.

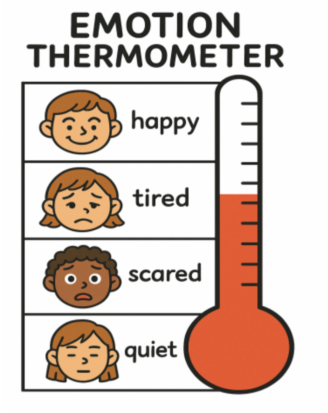

Figure 2. Emotion Thermometer Board showing illustrated faces to help the child identify and express emotions.

1.4.4 Family Support and Home Collaboration Strategies

Close collaboration with Amira's family will be vital to her educational therapy. Families caring for children with CLLC bring valuable insight into the child's daily rhythms, needs, and responses, making their involvement key to maintaining consistency across all settings. A Home–School Logbook will be used as a practical communication and collaborative tool, linking educators, therapists, and caregivers. The log will record observations of Amira's mood, energy levels, appetite (i.e. whether she finishes her snacks and meals), and any signs of discomfort. Information exchanged through this log will help guide daily therapeutic decisions and promote continuity across home, school, and medical environments.

The ET will also conduct coaching sessions for Amira's parents. These sessions will focus on how to use augmentative and alternative communication (AAC) tools, implementing sensory-friendly routines, and recognising Amira's emotional cues. This participatory approach strengthens emotional connections and supports a more stable environment for Amira's learning and well-being.

To support legacy work, Amira's therapy will include activities such as creating clay handprints, creating a playlist of songs that bring her comfort or joy, recording a video of bedtime stories to document her expressions and voice, creating a "message in a bottle" collection, where she draws for her parents and siblings and planting a tree with her name (see Figure 3). These symbolic rituals have been shown to offer families a sense of spiritual continuity and child-led memory creation (Iannello & Kellstet, 2022).

Figure 3. Tree planting activity as part of legacy work with a child.

1.4.4 Integrated Palliative Care Strategies

Working with classroom teachers, the ET will ensure that the educational program will be adapted to emphasise quality of life over academic mastery. Recognising her medical condition and fluctuating energy levels, her curriculum will centre on topics that hold personal relevance and emotional resonance. These include themes such as animals, colours, weather, and family, presented through sensory-rich experiences that are both familiar and comforting.

Instructional pacing will be gentle to accommodate Amira's stamina. Activities will be designed in short intervals, following a 15-minute engagement period with a 10-minute rest break. This study-break cycle aims to reduce cognitive and physical fatigue while still providing opportunities for interaction, exploration, and enjoyment.

A comfort space will be created using a sensory tent with soft lighting, calming music, weighted blankets, and textured objects. These elements are intended to offer physical comfort and build a sense of psychological safety when Amira experiences sensory overstimulation. This approach reflects best practices in paediatric palliative care, where creating sensory-sensitive, emotionally supportive environments is essential to maintaining dignity, autonomy, and quality of life during the care journey (Randell et al., 2022)

2. DISCUSSION

Children with CLLC often experience a gradual physical decline as well as significant emotional and psycho-social challenges. One of the key concerns in such cases is *affective decline,* which refers to the progressive weakening of a child's ability to process, express, and regulate emotions. This process is often influenced by a combination of biological, psychological, and environmental stressors linked to the child's condition. In Amira's situation, behaviours such as emotional withdrawal, decreased verbal communication and limited engagement with familiar adults during routines point to the possibility of affective changes emerging over time. These behaviours are commonly displayed in children with CLLC who experience ongoing discomfort.

Children with CLLC are also more likely to experience emotional vulnerability and psychological challenges such as anxiety, mood fluctuations, and depression (Stein, 2022). These challenges often lead to reduced social interaction and withdrawal from peers and or familiar adults (Boris et al., 2024). For children like Amira, emotional decline unfolds gradually through subtle changes in mood, responsiveness, and engagement. Pain, fatigue, perceived emotional threats, and the absence of social connection often influence mood changes. Chronic illness can impede socio-emotional development by limiting opportunities for emotional reciprocity, symbolic play, and peer belonging. EdTx, therefore, must be sensitively adapted to counteract these effects. Amira's multimodal intervention strategy scaffolded affective experiences through peer connection, sensory storytelling, music therapy, and legacy-building. This approach aims to preserve her sense of emotional identity, social meaning, and spiritual coherence, even in the face of cognitive and physical decline. These strategies are crucial for maintaining affective continuity and preventing emotional numbing or social isolation as the illness progresses.

ETs in palliative care settings hold an important role to bridge medical, school, and familial systems while attending to the child's psychological and spiritual needs. This work requires ongoing supervision, reflective practice, and ethical sensitivity. Chia (2025) emphasised the importance of supporting therapists in managing the emotional complexities of end-of-life care, especially when facilitating difficult conversations around anticipatory grief, death awareness, or symbolic farewell practices. In Amira's sessions, the therapist's ability to hold space for emotional truth while scaffolding legacy-making through clay handprints, voice recordings, and photo-memory books proved vital for both child and family.

Carstensen's Socio-Emotional Selectivity Theory (1992) offers further insight into Amira's shifting priorities. The theory posits that when individuals perceive their time as limited, they shift from future-oriented goals (e.g., skill acquisition) toward emotionally meaningful pursuits (e.g., connection, closure). Amira's preference for familiar songs and spiritually resonant stories illustrates this developmental realignment. By focusing on emotionally salient activities, EdTx aligns with dignity-based frameworks that prioritise presence, meaning, and connection over measurable academic progress.

Amira's engagement with sensory-based activities such as cooperative mandala drawing and AAC-based storytelling illustrates how EdTx can operationally improve functional and emotional development (Liu et al., 2020; Campenni & Hartman, 2019). Digital mandala colouring, using generative colour palettes, can also further extend these interventions by enabling nonverbal communication and multimodal self-expression (Roquet & Sas, 2021). These observable improvements in engagement and communication form the foundation for linking EdTx to measurable health impact frameworks such as the Disability-Adjusted Life Year (DALY) and Years Lived with Disability (YLD) metrics.

Traditionally used to quantify global disease burden (Murray, 1994; Murray et al., 2012; WHO, 2023), these metrics assess both the years lost due to premature mortality and years lived with functional impairment. In Amira's case, EdTx interventions do not alter medical prognosis but tangibly reduce the lived burden of disability by enhancing communication, participation, and emotional regulation. For example, increases in peer engagement, responsive communication, and adaptive emotional expression represent quantifiable improvements that translate into a reduction in her YLD, as it captures how psychosocial interventions improve the quality of life lived with the condition. When scaled within hospital or hospice-based education programs, such interventions can collectively decrease the overall DALY burden associated with paediatric neurodevelopmental and palliative populations, thus strengthening the public health value of EdTx.

At the same time, EdTx differs from other allied health and psychosocial interventions in its focus on learning as a therapeutic process. EdTx bridges cognitive development, affective regulation, and meaning making through structured engagement. While psychologists primarily address emotional processing, and occupational therapists target sensory or functional goals, ETs integrate pedagogical methods with psychosocial support, making teaching itself therapeutic. However, the scope of EdTx may be limited by institutional boundaries, its emerging recognition in medical settings, and the need for clearer interdisciplinary protocols to ensure consistency and collaboration across care teams.

At the systems level, barriers remain. Fragmented policies, limited coordination across sectors, and rigid assessment criteria often restrict access to comprehensive support for children with complex and chronic medical needs. As noted by Xue (2024), inclusive practice requires meaningful structural reform that embraces cultural responsiveness and coordinated efforts between the health and education sectors. In addition, there is also a need for harmonised and flexible family-centred polices to support the children and their caregivers (Zhang & Deng, 2023; Zu, 2024). Amira's case demonstrates the transformative potential of such alignment. When collaboration happens, children receive more consistent, dignified, and practical support, affirming their identity while addressing both medical and psychosocial needs.

2.1 Parental Identity, Relational Continuity and Legacy-Making

The role of the family, particularly parents, in the therapeutic journey of children with CLLC cannot be overstated. Mahler's (1975) separation–individuation theory provides a developmental perspective to understand the emotional complexities faced by these families. While typical child development allows for the gradual emergence of autonomy, this trajectory shifts significantly for a child with CLLC, where physical regression and a shortened timeline alter this dynamic. Her parents experienced both the pain of anticipatory grief as her condition progressed and the joy of emotionally rich moments that were amplified by the therapeutic process. Galinsky's six stages of parenthood (1987) further frame these experiences. The model recognises that parenting evolves from image-making to interdependence, with shifting goals and identity challenges. For Amira's parents, the emotional labour was concentrated in the later stages, particularly as they navigated the role of meaning-makers and memory preservers in a condensed period (Galinsky, 1987).

Spirituality also emerged as a protective factor for Amira's parents as it offers emotional grounding as they navigate through the grief process. Parent coaching in this context moved beyond behavioural strategies to include spiritual affirmation, anticipatory grief processing, and collaborative narrative work. The use of logbooks, coaching on AAC, and family rituals created an emotionally coherent environment that centred Amira's voice. Legacy-building interventions (i.e., planting a tree or recording voice messages) gave parents a role in co-constructing meaning with their child. These strategies align with research on dignity-based paediatric palliative care, which emphasises spiritual presence, relational continuity, and cultural grounding (Cai et al., 2023; Lin et al., 2024). Iannello et al. (2022) highlighted that spiritual rituals and cultural beliefs actively supported families' psychosocial adaptation, especially when they shape their caregiving practices.

Integrating EdTx within paediatric palliative care sees a shift in the therapist's role. Rather than focusing solely on academic support, the ET becomes a co-navigator in the family's experience of uncertainty. The therapist is now helping them navigate the emotional and developmental complexities of living with a life-limiting condition. In Amira’s case, the therapist served as a bridge between school, hospital, and home by scaffolding emotional literacy, fostering meaningful connections, and honouring life through shared memory activities.

3. CONCLUSION AND RECOMMENDATIONS

Amira’s case offers a window into the lived realities of children navigating CLLC. Her experiences reveal that beyond medical care, these children require an integrated model of EdTx that affirms identity, fosters emotional expression, and holds space for connection and meaning-making across developmental, spiritual, and relational domains. As the health condition of a child with CLLC deteriorates, ETs remain key figures in preserving the child’s sense of self and belonging.

Rooted in a dignity-centred care model, this approach centres on what matters most to the child. While Amira’s therapy plan illustrates one way these principles may be enacted, it should not be regarded as a prescriptive model but rather as an example that highlights potential directions for practice. Amira’s therapy plan—integrating sensory support, symbolic activities, peer connection, and family rituals—reflects how thoughtful, relationship-based interventions can uphold agency, continuity, and meaning, even in the most vulnerable stages of life.

Importantly, the goals of EdTx in such contexts do not aim for mastery or standard academic outcomes. Instead, it prioritises the child's experience of presence, choice, and continuity. Through legacy-building activities, spiritual rituals, and sensory regulation strategies, therapists can co-create spaces where paediatric patients are seen not solely as patients but as holders of memory, imagination, and connection.

As health systems strive for greater integration of psychosocial care into paediatric palliative support, the role of ETs will continue to evolve. ETs will require access to sector training, collaborative supervision, and policy support to sustain ethically sound and culturally responsive practices. These developments also point to a need for sustained research examining how EdTx models can be adapted and scaled across different cultural and institutional contexts. Future studies could explore correlations between EdTx participation and improvements in communication, emotional regulation, and adaptive functioning, all of which are key domains reflected in the Years Lived with Disability (YLD) component of the Global Burden of Disease framework (Murray et al., 2012; WHO, 2023). Qualitative studies are also essential to capture the lived experiences of children, families, and therapists across the globe in diverse cultural and institutional settings, particularly in dignity-based care. Amira’s case reminds us that even when complex chronic health issues can be life-limiting, the quality of emotional connection, the child’s dignity, and worldview can also be protected and documented as part of the legacy.

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5. COMPETING INTERESTS

The author has declared that no competing interests exist.

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7. ARTIFICIAL INTELLIGENCE DISCLOSURE

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