

## Art-Based Interventions for Children With Terminal Illnesses

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### Abstract

Children with terminal illnesses call forth a number of challenges for not only the young members of any family but also jeopardize the equilibrium of the entire familial context. Art-based interventions help to address emotional distress, enhance resilience and promote positive self-expression among chronically ill children and also among other members of the family apart from improving communication. They further help to overcome their stress and psychological shock at the awareness of having a terminal illness in the personal front. It is based on the premise that such interventions at the therapeutic level provide participants with an opportunity to express their unstable emotions, so as to relieve tension and feel better during times of spiritual and emotional hardship. The creative process of ‘meaning-making’ enables participants to accept their emotions naturally and facilitates acceptance of their diverse feelings through the process. The present theoretical paper explores the different commonly used art-based interventions that may be used for this sub-sample, some being painting, storytelling inclusive of digital storytelling (videography), puppet-making, poster-making, collage-making etc. Such interventions not only help in improving communication but also foster coping among children and significant others in the family. The authors have also suggested a specific art-based therapeutic session plan, which may be specifically applied for such children. Implications of the study have been discussed.

**Key words:** *Art-based interventions, children, terminal illnesses*

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Life-limiting and life-threatening illnesses (LLIs and LTIs) may sometimes unfortunately befall young children, bringing forth heavy challenges on the entire family. Such illnesses may take the form of progressive metabolic, neurological, chromosomal conditions along with cancer that appear to scathe and jeopardize the family-context completely. They may accompany unknown illness trajectories and lifespans, along with unpredictable emotional crises (Bally, Burles, Spurr and McGrath, 2023; Burles *et al.*, 2022; Burles *et al.*, 2021; Derman & Deatruck, 2016). The quality of life (QoL) of both the children and their families are consequently at stake. Families often grapple with the shock of having such an untoward condition that they could ever have imagined, and are often considered as families' worst nightmares (Bally, Burles, Spurr and McGrath, 2023). Effective communication of parents and other significant others with the child/ children suffers as a result gravely. The need is palpably felt to provide some therapeutic interventions primarily for children along with their families, if possible, to help them support adaptation to stressful, traumatic health experiences (Jithoo, 2010; Smith *et al.*, 2018; Doherty *et al.*, 2009). The present theoretical research article attempts to explore the nuances of different art-based interventions for such sub-sample.

Art as an intervention technique as well as a research method for collecting data in a non-threatening manner has been used quite extensively among children and families (Cho *et al.*, 2022; Bryan *et al.*, 2019; Hyslop *et al.*, 2018). Such interventions in hospice palliative care involves a holistic approach to improve the overall quality of life (QoL) of participants in their final stages of life. Digital story-telling (Cho *et al.*, 2022; Akard *et al.* 2015), puppet-making (Sposito *et al.*, 2016), drawings (Abdulah and Abdulla, 2018; Angstrom-Brannstrom & Norberg, 2014) and painting (Schaefer *et al.*, 2019) are some important arts-based outlets meant for expressing the self creatively in different forms. Art-based activities and interventions have the beauty to be child- and family-centric and can be applied for different

ages and developmental stages (Woodgate *et al.*, 2014). They also involve low cost and are simple to implement. Such therapeutic sessions enable participants to confront mortality by increasing their acceptance of death anxiety and existential concerns, bolstering family resilience, enhancing their sense of connectedness with others and improving self-expression and quality of life (Safari, 2013; Park and Kim, 2018). They help to improve self-awareness, and express themselves during a time when it is difficult to verbalize their experiences of suffering, confusion, and contradictory experiences of life, amidst providing social support for family members and caregivers (Malchiodi, 2013). Participants themselves can gain a sense of autonomy and accomplishment during the course of their creative journey to recognize that they are still individuals of worth despite their illnesses (Lin, Moh, Kuo, Wu, Lin and Tsai, 2012; Wallace *et al.*, 2014).

### **Improved Communication as Fostered by Art-Based Interventions**

Research has indicated that art-based interventions addressing young children and adolescents with serious illnesses like cancer enable them to articulate their needs in a non-threatening manner (which are otherwise difficult to verbalize). They foster meaning-making of young minds amidst an ambience of uncertainty and guilt, discomfort, overwhelm and confusion (Arruda-Colli *et al.*, 2015; Angstrom-Brannstrom & Norberg, 2014). Art-based interventions help to improve communication with health care providers to enhance their understanding along with their families regarding their illnesses (Galvez *et al.*, 2021; Linder *et al.*, 2018; Manning *et al.*, 2017). For instance, human figure drawings (HFDs) (Koppitz, 1968) have been found to be able to evaluate emotional well-being of African school-aged children effectively in palliative care (Brits, 2018). A child was noted to use drawings of a dragon as a metaphor to explain the diagnosis and relapse of cancer to depict his experiences to others. Furthermore, the drawn figures serve as stimuli to initiate discussions about emotions and other challenges that the children are facing.

Apart from children's treatment regime and hospitalizations because of their life-limiting and/ or life-threatening illnesses, which may be stressful for both the children and their families, young clients may also suffer from added fear of strangers, being away from home and possible separation consequently, making effective communication and social context to serve as important pedestals of nursing practice of the family. Photographs along with drawings have also been used together to explore the experiences of children aged 4-12 years undergoing chemotherapy (Gibson *et al.*, 2012). They harp on children's willingness and ability to share their experiences with art-based interventions addressing client and family care effectively (Massimo & Zarri, 2006; Packman *et al.*, 2008; Rollins, 2005).

In addition, "draw and write" or "draw and tell" techniques along with journaling using computerized drawing tool appear as effective data collection methods to explore the inner world of children suffering from cancer (Galvez *et al.*, 2012; Woodgate *et al.*, 2014). They may enable to tap into the most commonly experienced feeling tones like sadness, frustration, fear, irritability, and anger, along with strategies to self-manage their symptoms (Manning *et al.*, 2017; Woodgate *et al.*, 2014). Digital drawing tool enable the children with meaning-making of their experiences by using their imaginations to explore their feelings. Other drawing tools like Human Figure drawings (HFD) and Kinetic Family Drawing (KFD-R) can effectively assess different aspects of family dynamics and distress, if any, as experienced by the participant. Furthermore, the use of painting and handcrafting as art-based interventions help to improve quality of life by increasing social activity participation, more social relationships, and enhancing overall health (Abdulah & Abdulla, 2018). Consequently, meaning-making of their social contexts, experiences, hopes and dreams for healing, recovery, quality of life and comfort often are reflected in the art-based activities (Cho *et al.*, 2022; Rollins *et al.*, 2020). Such activities provide a means to focus, share, and understand their feelings. Pictures drawn by children may be assessed for use of colors, content, size of

objects along with the application of Emotional Indicator scale to evaluate them (Skybo *et al.*, 2007).

### **Art-based Interventions as Fostering Coping Mechanism Among Children and Families**

Art-based interventions and research methods can support coping in children and families throughout their illness experiences, with the products of such activities projecting the inner turmoil of the participants. Both family members and children may jointly engage in such art-based projects (eg. making collages together), and symbolize legacy-making, with children and their parents, making them feel much better along physical, spiritual, emotional and social aspects. Such activities may also address family health as a whole since families often suffer from significant lack of control and social isolation when a child is treated from a LLI or LTI (Arruda-Colli *et al.*, 2015; Vindrola-Padros, 2012). Such family art therapeutic sessions help to uncover positive resources and improve communication in the family (Walsh and Weiss, 2013). Art-based legacies leave participants with tangible product/s and memory associations that may help to improve loss and bereavement later in life (Schaefer *et al.*, 2019; Katherine, 2014). More open discussion about the challenges faced in the familial context may enable the participants to verbalize and communicate the same to others for greater awareness and to bring back a sense of balance in their lives. They may attempt to capture the plethora of experiences and emotions that children, parents, and siblings go through when a young family member goes through significant life event in the form of a LLI or LTI, which is expected to impact family relationships and family reorganization drastically. It is through drawings that children are able to express aesthetically the interpersonal relationships whom they bank more for deriving social support. This helps them to have a deeper understanding about children's ability to manage pain, and the struggles and limitations imposed by hospitalization & illness with the support of their families. Symbols representing their experiences like stories involving weather and threatening situations are

often used by children and adolescents to depict their existential concerns and worries. Art-based activities foster bonding experiences for families and usually contribute to a lasting memory which have potentials of being cherished by everybody. The images and artifacts created during art therapeutic sessions become a medium for expression and healing by helping the participant reflect upon the different episodes of his/ her life (Jones, Warren and McElroy, 2006). Both the participants as well as family members feel empowered during the process, deriving greater understanding and solidarity during the process of collaboration so as to express their grief and anxiety about losing a family member to death. Participants get the scope of reflecting on the meaning of life and to realize how precious they are to each other, confirming love and appreciation towards family members and preparing for death amidst spending meaningful family time during the span that still remains (Park and Song, 2020).

Art-based activities addressing reorganization in family dynamics due to the LLI or LTI in a young child/ children may involve drawing a feeling mandala, creating family drawings, discussing an animal metaphor etc. (Wallace *et al.*, 2014). Visual story-telling techniques may also come to be of help to deal with significant role-changes of parent/s (like loss of employment due to increasing demands to look after the ailing child, relocating to other places for seeking treatment facilities conveniently, interruption of education of siblings or hindrances posed to their education etc.) due to challenging and increasing demands in the family. As such, the incorporation of art into nursing practice and research can expand the social and emotional health of children and their families. The plethora of communicative possibilities for children, siblings and parents brought about through engaging in art-based endeavours include an enhanced ability to express symptoms for the ill child along with catering to the needs of all family members (Hyslop *et al.*, 2018). They offer an emotional outlet to different emotions in a non-threatening manner and are empowering in nature (Brits,

2018). Participants feel that they are being heard, making them feel more autonomous and confident, prompting feelings of self-efficacy, and greater engagement in health care activities (Sposito *et al.*, 2016).

### **Tailoring Art-based Interventions for Children with Terminal Illness**

Reaping the benefits of different art-based interventions with regard to overall family health of children and their significant others, the authors felt the need to design a therapeutic intervention plan for children having LLIs or LTIs. An art-based therapeutic intervention tailored for young children and based on eight consecutive sessions (once weekly for a duration of 1 hour- 1 ½ hour) has been suggested which is detailed below:

**Table 1**

*Suggested Art-Based Intervention Programme Tailored for Children with Terminal Illness With Each Session (Once Weekly) Having Duration of 1Hour- 1 ½ Hours*

<b>Session</b>	<b>Detailing of each art-based therapeutic intervention session</b>	<b>Psychological implications associated with each art-based therapeutic intervention session</b>
1.	Introductory session: <ul style="list-style-type: none"> <li>• Introduction of self</li> <li>• Intervention using drawing and painting [eg. Human Figure Drawing (DAP), Draw-a-Person in the Rain (DAPR), Kinetic Family Drawing (KFD) etc.]</li> <li>• Exercises involving ‘drawing and writing’ or ‘drawing and telling’</li> <li>• Sticker activity to communicate the feeling tones or drawing a feeling mandala</li> </ul>	Self-awareness, better communication, expressing feelings that are difficult and cannot be articulated with words
2.	Intervention using drawing and storytelling: <ul style="list-style-type: none"> <li>• Drawing-and-Story Procedure</li> <li>• Open-ended interviews &amp; and dignity therapy interviews with the client</li> <li>• Taking down field notes and life retrospective notes from family members</li> </ul>	Improved communication
3.	Intervention using videography (digital story-telling):	Self-motivation, developing resilience

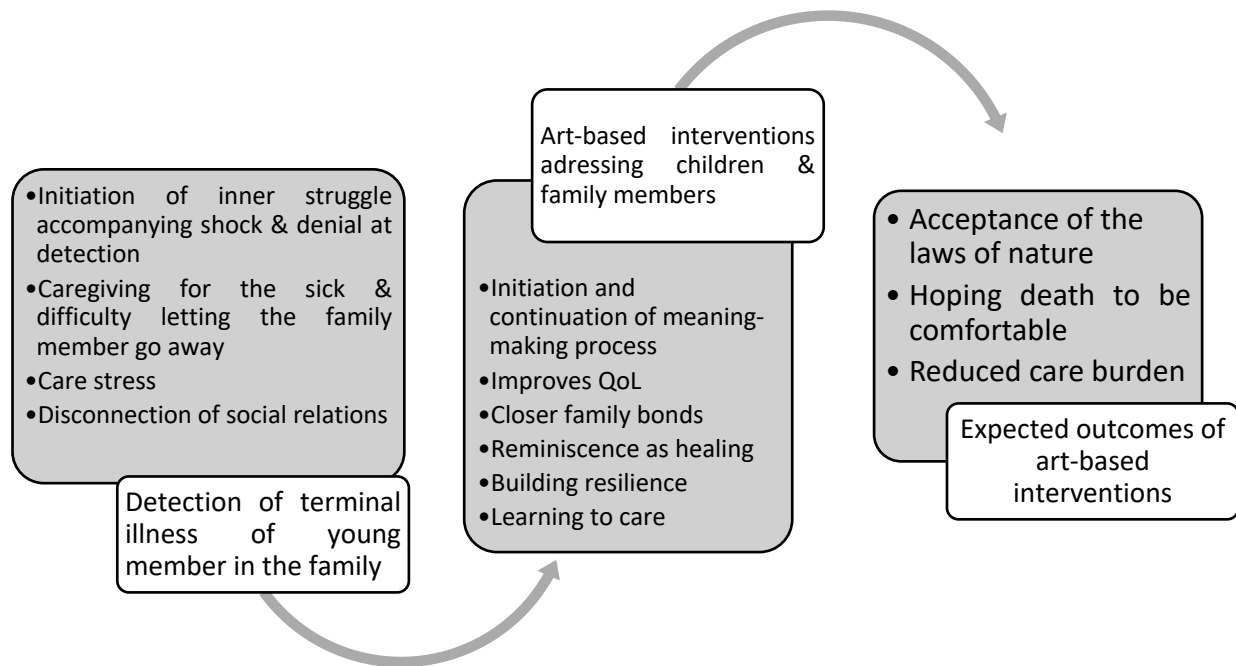
	<ul style="list-style-type: none"> <li>• Participants are encouraged to focus on what they want to be remembered (songs, photographs, crafts, voice etc.)</li> <li>• Legacy intervention: Creation of digital storyboards that may be kept as family keepsake later</li> <li>• Family story: Magazine collage journal</li> </ul>	
4.	<p>Intervention using ‘mosaic method’ in creating posters</p> <ul style="list-style-type: none"> <li>• Encouraging participants to make posters with drawings, photographs and text which provide them a sense of hope</li> <li>• Discussing about the posters through ‘Draw and Tell’ technique of storytelling</li> <li>• Facilitation of semi-structured one-to-one interviews with the older participant (12 yrs. or older) based on whatever he/ she has created and what does it mean to him/ her</li> </ul>	Developing resilience, engaging in optimistic thinking
5.	<p>Intervention using puppet-making &amp; story-telling</p> <ul style="list-style-type: none"> <li>• Encouraging children in puppet-making based on developmental and visuo-motor perceptual ability</li> <li>• Engaging children in story-telling with the created puppets</li> </ul>	Improving communication and emotional connecting
6.	<p>Intervention using painting, drawing and clay animal-making</p> <ul style="list-style-type: none"> <li>• Clay animal-making</li> <li>• Painting the created animals</li> <li>• Engaging in role-playing and story-telling through the created animals</li> </ul>	Improving communication and emotional connecting
7.	<p>Creating a Memory Box:</p> <ul style="list-style-type: none"> <li>• Intervention including scrapbooking, crafting for children aged 4-6 years;</li> <li>• Interventions using diaries and drawings for children aged 7-12 years</li> </ul> <p>In-depth interviews with participant’s parents</p>	Developing resilience, aiding in improved bereavement of family members
8.	<p>Intervention with the entire family:</p> <ul style="list-style-type: none"> <li>• Using photography, painting, collage, drawing, writing and sharing objects as gifts among family member</li> <li>• Hand imprinting (by participant and family members)</li> <li>• Artwork as a keepsake for the family</li> </ul>	Engaging in family time, improving family QoL, improving communication, developing resilience, improving bereavement of family members



As such, art-based interventions operate on the following paradigm:

**Figure 1**

*Paradigm Followed by Different Art-Based Interventions for Children With Terminal Illnesses*



(Source: Authors)

### Conclusion

Detection of life-limiting and life-threatening illnesses among young members in a family can be shattering for everybody, leading to shock and denial of the diagnosis. Communication is quite naturally disturbed in such a context. Therapeutic interventions based on arts enable to provide a healing ambience by initiating meaning-making, improving self-awareness, and communication within family members, building resilience and accepting death gracefully. They work at a holistic level and may involve drawing, painting, storytelling, collage-making amidst other creative techniques to express themselves proactively. The article also engages in the academic endeavour of suggesting a tailored

therapeutic programme for young children and adolescents based on such art-based interventions. Such practices are likely to be promising as regards their implications.

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