

Little Hands Say Goodbye: An Art Therapy Manual for Pediatric End of Life Care

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Background

•Holistically addressing psychological, social, and spiritual pain of children and adolescents and their families (Canadian Hospice Palliative Care Association, 2006), end of life care seeks to preserve dignity and quality of life for patient's who face an incurable disease (Widger et al., 2012; Wood, 1995).

4 Aims of Art Therapy in End of Life Care were conceptualized:

Visual imagination through art therapy decreased perceived pain and nausea (Madden et al.,

 Art therapy techniques through narrative therapy & medical play helped manage anxiety & fear, especially fear of treatment (Bultas et al., 2017; Council,

> Symptom Management

Increasing Locus of Causality

- Art therapy helped increase reiliency, self esteem, and overall emotional self concept (Beebee, Gelfand, & Bender, 2010; Malchiodi, 1998).
- Art therapy approaches increased patient's sense of control, decreased hopelessness (Ducker, 2015) and increased independence and mastery.

Saying Goodbye

family to say goodbye while also and can serve as attachment objects for the family (Smith & Rubin, 2017)

Acceptance

• Narrative approaches to art

therapy help reframe stories in

1998; Massimo & Zarri, 2006).

order to assist children in coming

Art therapy can assist in addressing

existential questions in a space of

imagination (Bissonet, 2015) and

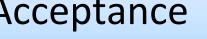
emotions (Luginbuehl-Oelhafen,

2009).

giving room to wrestle with intense

closer to understanding (Malchiodi,

- Art provides a space for the child and creating lasting memories (Councill & Ramsey, 2019). Art is deeply symbolic
- Children are able to leave unique marks to ensure they are seen and remembered by others (Picirillo, 1998).



Addressing Gaps

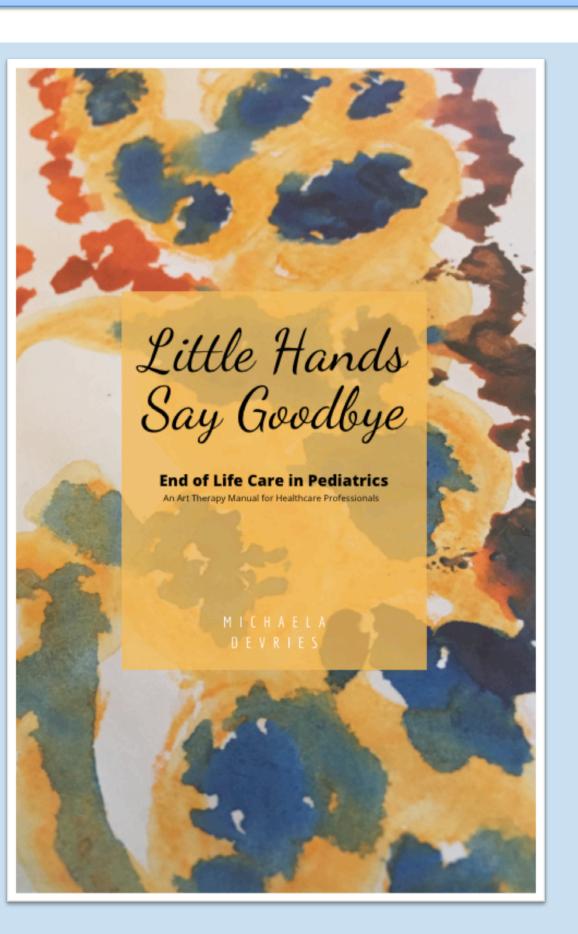
- The interplay and importance of culture and religion on end of life care was poorly represented. There was also a lack of evidence showing work in end of life care in developing nations.
- Cancer is a leading cause of death in children (Statistics Canada, 2015) therefore leading to an abundance of research in this field. There was a lack of research regarding other childhood diseases and perspectives of end of life care not related to cancer.
- •Art therapy literature was often written for other art therapists and artists but rarely for the health care professionals to understand art therapy better. This capstone hopes to expand on this gap by designing a manual for health care professionals.

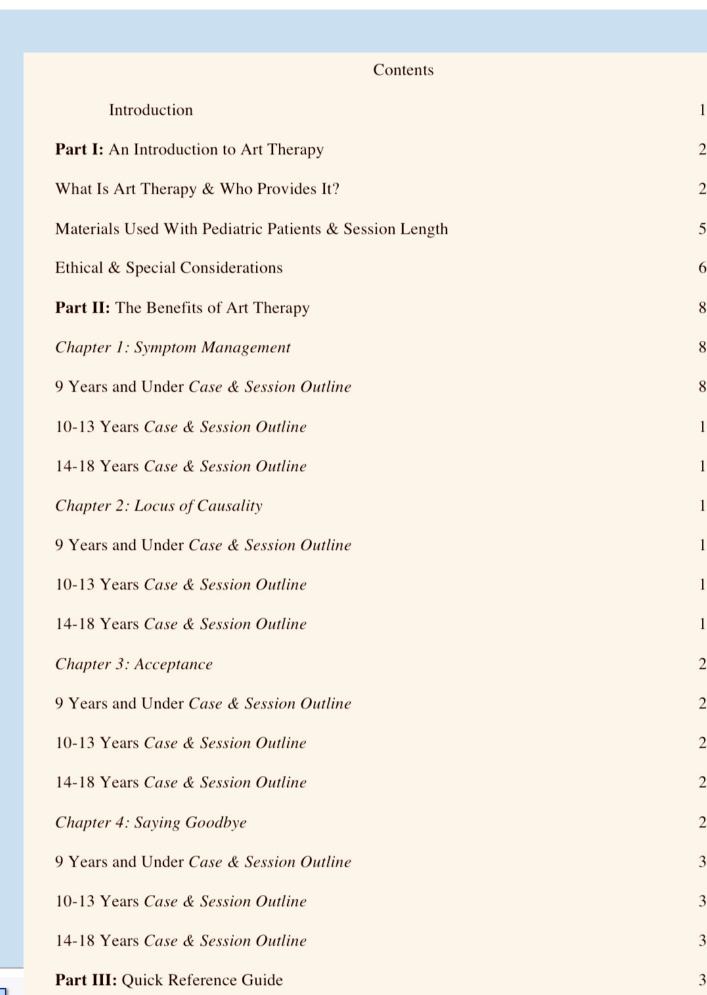


Rationale

- Personal Rationale: Through the challenges of losing a parent at a young age, I have often sought answers to many questions, including why and how we die? What does a *good* death mean? And how can I be of service to the community? This capstone is an attempt at answering these questions, in gaining more knowledge and insight to the end of life.
- Professional Rationale: To bridge the understanding for health care professionals of the kind of work art therapists do in pediatric end of life care. Art therapy is beneficial and how can this knowledge be shared with health care professionals and the wider community? Combining my competency building with my art therapy activism.

The Manual





Feasibility & Material

- The publication of this manual is highly feasible, with the ability to print and create a book cover available to the average person.
- Networking within the palliative care sector is needed in order to deliver the manual to the intended audience. Attending end of life care conferences and connecting with the professionals who may utilize this manual is necessary.



About the Manual

- Designed for health care professionals who work in pediatric end of life care.
- Providing an introductory look at the basics of art therapy. The manual addresses FAQ's of art therapy related to the profession and specific questions about art therapy work in end of life care and pediatrics.
- Outlining the aims of the literature review (symptom management, increasing locus of causality, acceptance, and saying goodbye), the manual provides comprehensive literature, case and session outlines of each aim, and artwork. Providing readers with background and examples of art therapy.
- The manual also includes a "Quick Reference Guide" as an overview for busy professionals.

Future Work & Research

- Moving into work in palliative and end of life care, this manual serves as a packaged way to introduce the benefits of art therapy to a future employer or management who may be interviewing art therapists. I hope to pursue future work in rallying for more art therapy jobs in healthcare.
- Moving forward into an international practice. I would like to dive deeper into the differences of end of life care cross culturally and in international work.

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Reflections

- Through this process I became aware of the physical and emotional barriers that burnout can create. Pragmatically, it is essential to have colleagues and individuals around you to help notice your burn out as a professional. This is of great importance to all professionals, especially those working in end of life care.
- In my research, I was able to experience the resonance of compassion in the work of end of life professionals. I passionately want to be a part of the meaningful work being done in end of life care both with adults and pediatrics.

