**SACRED MEMORIES:
CREATIVE ART THERAPY FOR CHILDREN
IN GRIEF.**

by

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ABSTRACT

This paper explores the creative opportunities children might have to attend to their emotions and feelings following the death of a parent, grandparent or close friend. It presents the position that often children are left out of the process of caring for an adult when they are terminally ill and that has long term psychological implications. It also suggests that this has antecedents for the white New Zealand culture that were noted historically.

Hospice palliative care services in New Zealand identify the need to be proactive in their holistic care for the family when a person is dying and this care must include the family which invariably includes children. In this research the author describes a personal journey that has shaped her current work as a hospice practice manager. She has chosen to highlight a neglected aspect in services in New Zealand.

The writer explores literature in psychological aspects of removing children from the dying room, creative therapies and the importance of sacred memories for the living child to be enfolded in through their life.

The need to create memory that will embrace the child as a cloak enfolds them in their crisis stimulated the writer to offer a

text in the personal narrative form. This text is presented in this form to enable other clinicians to access their own memories as survivors of grief in their own families.

Through enabling children and family to explore the importance of relating in the palliative phase of a person's life journey it is suggested that doors open that build good memories for the survivors.

I regard my specific form of interest as pursuing the idea of building memory creative 'corners' and fun experiences for children at my work. The reasons why such an experience would be beneficial now and in the future for children and their families will be the focus for conducting my literature research.

Children were important in the final days of her father's life. He directed the family to accept the roles he saw would be theirs.

Memories became their treasures.

ACKNOWLEDGMENTS

I dedicate this paper to my Father who in his dying days encouraged me to enroll in the Masters Study program at Victoria University.

To my husband and children I acknowledge their support and patience and computer skills my daughter has endeavored to instill in me during my years of study.

I acknowledge the support and encouragement of my supervisor Dr. Margie Martin, my critical friend during my Masters study Liz Horn and my colleague during this year Jane Maries.

Thank you all.

PREFACE

Spirituality is the challenge bringing a human to wholeness of being. That was the challenge for my father in his life.

Death brought completeness to his human life.

His life challenged me to explore the creative memory formed during my life with him and the professional journey I travel to explore ways that permit me to touch another human in the caring moments of my palliative care practice.

The being in this practice touches me as I open the door to touch the life of another human in this moment.

As I open my personal experiences and story I ask the reader to enter an imaginary door, sit with the narratives that describe my world of practice and become immersed in their own world. I have included narratives on my personal and professional life and identified challenges for the future of my palliative care practice with the aim of encouraging other clinicians to create an environment that allows for good memories to form from their own moments of caring.

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GLOSSARY

Palliative Care

Palliative care is the total care for people who are dying from active progressive disease or other conditions when treatment for cure is no longer effective or possible. Treatments relate to physical, spiritual, emotional and social needs of the patient their family and whanau.

Family or Whanau

Family or whanau is who the person states are important to them at this stage of their life journey. e.g. wife, partner, child, friend or family member.

Children

People known to the patient, their family or whanau, dependant on another person for life skills. The child is usually under the age of sixteen years, but special circumstances may denote age.

Art Therapy

Art therapy is the creative opportunity available to enhance the expression and exploration of inner feelings and may include relating these feelings to another person such as a family member or person working within the health profession. It may include but is not limited to narrative, drama, drawing, sculpture, music, poetry or puppetry.

INTRODUCTION

There is a saying by hospice palliative care practitioners in New Zealand, Australia and the United Kingdom that people have a “good death”, a ‘good enough death’ or ‘not a good death’. This relates to the perception of the professional relating the narrative. The key for me is finding the words deep within myself to create within conversations with my patients the caring moments that are for me the essence of palliative care.

Hospice palliative care includes the patient, family or whānau and the family or whānau frequently includes children. Family will include for the purpose of this research project a carer who may be a spouse, partner or a nominated friend, and their dependant or non-dependant children.

My interest relates to the delivery of the care to the patient and will include their family in this dying stage of their life in a rural city in New Zealand. This is not a reflection of the process of children dying and their grief but of children within a family setting experiencing a death within their family or extended family.

Through the process of reflecting back on questions asked during reflective practice, inservice education sessions, informal sharing with nurse colleagues, sharing in bereavement groups and with patients and their families allowed me to reconsider the philosophy of care that is central to my nursing practise. Through an academic project involving developing insights and artefacts that would represent the aesthetics of my practice I chose initially to identify what was not present in my practise work arena.

I realised that while working with staff, children, adults and families in bereavement groups, my own journey or story of life form an important part of the basis of my hospice palliative care nursing practise. Many times families have shared what is worrying them and asked for advice on what they should do with their children during the dying phase of their family member's life journey. They have often engaged me in conversation bringing questions relating to what the children were asking, or what the children had identified and what they were doing at this time within their family.

I recognise the significance of these revelations through stories families shared and reflected on my experiences

professionally and personally as a means of developing my philosophy of practise.

Nursing stories and experiences in the New Zealand palliative care field are honoured and acknowledged for their humanness and uniqueness in practise settings and all levels of educational endeavours and research.

As a hospice palliative care nurse with many years experience in the bereavement support area of the service I have observed scenarios similar to those that families revealed documented in palliative care literature of post death experiences. I acknowledge in my philosophy of nursing the need for intervention for children to improve their health and ability for them to cope through the building of family bonds and traditions in their future life. I state that this is my position in conversation with families so that they will have a means to consider what is occurring. This thesis project provided the perfect opportunity to deepen my resources through further exploration of the opportunities and experiences available for children as a way of initiating the grief experience process through creative projects within literature. This opportunity enabled me to explore how children delve into their memories at a later date

during a grief journey. Most importantly for my practise and work environment in a hospice the project and subsequent thesis has clearly shown the benefits from identifying and exploring creative opportunities within families with children involved with an adult who is dying before the death occurs.

The long-term vision I have as an outcome for the project is to gather creative materials and create a corner in the Hospice and/or car for use in and by any child or adult. I consider that this creative exploring requires being brave enough to meet their inner self at this particular moment in time for them.

Inside the door of my practise world or inside my philosophy I have come to consider that the memories each individual retains following a death relates to the person who died, the dying process and place of death and the professionals providing the care. This event fills their being and similar experiences in the future will reflect on this experience throughout their whole-life especially in crisis situations. This, their memory, will shape their health, self-esteem and relationships and will be reflected in the health needs of themselves and New Zealand society in the years to come. This wide angle

view sits comfortably with me as the detail of the individuals story in a family life are special and have their own parameters that encompass memories and visions.

In contrast are the memories and sad stories adults often relate within bereavement groups revealing how when they were children they were shielded from family members who were dying. Or it might be a scenario of contemporary times that was brought to my attention. The story of a child arriving late to school and upon sitting down at her desk started to cry. The teacher, who related the story, asked what was wrong, expecting to be told a story about being late to class. The child replied that her mother had told her on the way to school that her grandma had died early that morning. The teacher was then in a situation in which she received the news from the child and was relating her situation to me the nurse. It appeared no further discussion followed between the mother and child.

Many questions came to my mind on hearing this story. The lack of communication between this child and her mother about the death of a significant person and the subsequent seeming exclusion of the child during what I would have imagined would be such an important family

event. I also appreciate that while it is common in my world of work as a palliative care nurse manager to discuss death that it is not necessarily the case in all New Zealand families. None the less it still shocks me and puts the need for such a project sharply into perspective. I have not explored in the literature the psychological impact to the child of receiving such news or the adjustment of going home to a house without grandma who had always been there for the child after school. This must be considered along with the future mental health of this child in their adult life. Worden (1996) and Lamers (1999) write of the benefit of providing opportunities to explore through creative experiences during fearful times critical experiences or events in the life of the child.

The inclusion of art as therapy in the weeks, months and days prior to a family members death for a child allows them to create memory books or boxes that were their own. Creating ways to express the inner turmoil during this time enables a positive foundation for relating within the whole family by enhancing opportunities for sharing and support for one another in their painful time.

Being able to state that a culture that cares for, gives birth to, treasures and motivates child interactions will hopefully lead to positive experiences for the child and a

mutual articulated experience for the dying person and their family to enhance and create healing together must be central to our culture.

Palliative care is not related to any specific ethnicity or culture but encompasses all people regardless of class, culture, ethnicity or creed.

Guidelines or organised protocols will not be a part of this project as this is a person-centred vision for patients and their children, families or whānau to participate in if they desire. I have envisioned that this will open the door to the philosophy and culture of our Hospice.

REFINING MY AIMS - SEARCH STRATEGIES

During the process of searching for appropriate literature I refined the focus of my project and made the link between using the literature to clarify the narratives of my practice, more precisely, what worked to create sacred moments in times of family grief particularly for children. Through my work I have received stories from bereaved families that have stimulated my interest in ways children cope with palliative or very sick family members dying and how both the children and adult searched for and found 'normality' for them each day during this journey.

What occurred to me as I focused on the many shared stories was that there was a common narrative relating to not being allowed to be present at a significant persons dying or funeral that in the telling revealed significant implications for the person.

For example one person related how as a young child she had been sent to another town, 'for a holiday' and on return went to live with her aunt because her mother had actually died while she had been away. Nothing could help with her depression in adult life and the

anxiety she experienced in dealing with sickness and crisis. I recall being told this story in the hospice setting. I felt very moved by such stories and provoked to establish a way to enhance and empower creative memory building for all ages. I knew from my own nursing experience that conversations and evidence from the literature could be literally actively placed alongside the memory to provide the opportunity for life review and the development of positive real life experiences around life and death.

I commenced my literature search at the Victoria University library data base, using 'CINHL' and 'Pubmed' web sites with the words: child, bereavement, coping, creative therapy, counseling, grief, hospital, pre-school and dependent child. Minimal information was found on these sites that related to my search and so I opened the search to include sites within 'PROQUEST', 'GOOGLE' and 'AMAZON' world wide web. I joined palliative, medscape and pediatric, oncology, cancer and nursing centre news sites and 'EPERC' concentrating on the words: art, therapy, children, relative and dying. Articles were obtained that were relevant but more was needed.

Hand searches followed at local Hospice and Hospital Libraries. Palliative, cancer and medical journals, New Zealand Hospices, the Cancer Society Library and friends were assessed for their knowledge of articles or relevant information areas. Colleagues suggested magazines and books and my supervisor had prompts to spur me on always. Contact through a friend put me in touch with a palliative care nurse specialist in Australia to obtain information of computer links, sites and web pages.

I recalled Elizabeth Kubler-Ross at the workshop I attended in 1987 in Masterton, New Zealand speaking of her work with children who were dying. She used the caterpillar to butterfly metamorphous when explaining the transition of life to death experience with children. This challenged me to bring my topics and search back down to what I had really decided on as my interest for this literature search, which I commenced a few weeks earlier. In order to nurture my dream, give a concrete base to my search, I needed to lift the precious moments from my professional experiences and reflect on them in a positive manner to explore ways I have discovered worked in families previously. The awareness within this reflection related to communication and sacred moments

shared within families and how children were acknowledged and nurtured during the special memory building times.

The narratives recorded are fictionalized to protect individual families. I acknowledge the delicate nature of narrative within family with the unique cultural rituals familiar to each individual family. My personal story is the only story that portrays completeness in the relating. I have used this story to put myself and the reader in a closeness to my nursing culture, practice, knowledge and memory that will enable us to explore ways outside our present practice and look towards future practice.

Stories remain alive in our family through photos, memory boxes and collections along with the memories created over the month of my father's illness. These are living memories that I now open to colleagues in my desire to invite them to reflect and create with their patients and families knowing ways for them alongside evidence to explore with others in their life journey.

Nurses along with all health practitioners need to be open to

“transcend traditional professional boundaries and

come together to share unabashed love for caring and healing practices, integrating the human-nature-universe relationships in artful, aesthetic, healing practices and bring together art, science and spirituality to a new depth for those engaged in healing work” Watson, (1999, p.19).

This I believe is possible through narrative for me in my practice and through this search the door has opened to let in light to obtain the knowledge I searched for.

BEING IN NARRATIVE

The beauty of narrative is in the privilege of the intimacy of the narrative. The moment of sharing between the two people is the moment of trust. This is the sacredness of the moment bringing beauty and life in the telling or retelling of each story in the narrative chosen.

The narratives recorded come from the unique position of being within a unique family – my family – and the specialist palliative nursing field that enables me to have the privilege of walking with families in their unique journey.

At the beginning I record a close personal journey that opened the door to enlightenment. As I engage with the reader I ask you to be there within the caring moment of the narrative.

This is a special story of a unique 80-year-old man, my father, who I will refer to as L.

L was diagnosed with an enlarged liver secondary to an unknown primary cancer presumed to be from the lung or bowel. He chose not to have investigations to find the

cause of his disease and would receive palliative care for his symptoms. Pain, nausea, vomiting and constipation being his primary symptoms and relief was obtained with medications. L had three married children, one being myself, nine grandchildren aged 12 to 28 years and a great grandchild of one year. L, with myself and other family members, his palliative care nurse and medical team, discussed his discharge home from the Hospital via the Hospice to reassess his medications and needs. His wish was to be cared for by his family at his home until his death. Family relationships enabled this wish to be attained. All were able to spend a special family time together with L as the orchestra conductor in this his last waltz. During this time he believed his job was to cement his children into their new role as the older generation and to prepare his grandchildren for their life without a living grandparent. The family home with all present, became a special place for each individual family member as they built memories, remembered and helped L. to relate his life experiences as he empowered them to live a life without him present in the future.

Family times were of the utmost importance for all. Shared meals, card playing, watching the races, music,

garden advice, painting, maintaining property and just being together as they shared in the daily life of each other were most important and engaging moments in each day. Family members were joined by extended family to play and pray together in a manner that reflected their Irish cultural historical traditions, values and a togetherness that would continue to be a strong bond in their future. L had his 'memory box' out frequently sharing and engaging family in the stories that were attached to each treasure. The precious 'stuff' of his life experiences and joys were given when he found it appropriate to individual family members for their treasure boxes and books.

As the sun set on L's grave the memories of his life came to the fore empowering all to stay close, to support each other, listen and share during their life crises were central to the moment. Having been active in this journey, observing and reflecting on the interactions between all the family, including the older and extended family, I noted a growing support system that has stayed active to the present time. This was evident and strengthened when a second family member died a week later and family moved close to protect it's

members with the building blocks L had cemented in the wall for them.

My second reflective narrative relates to my practice and a very special family that included and enveloped me to their family. As I reflect on this experience I see how the light crept through the open door and empowered me in meeting the needs of each family member.

I well remember P – a sixty-six year old man. P and his wife Z were planning retirement and an overseas trip to P's extended family and historical roots.

Z who worked in a medical practice was offered a personal medical check on her resignation in preparation for the planned event. On examination a lump was detected in Z's breast. Surgery followed by radiotherapy happened quickly. Finally the holiday planning appeared to be possible with Z's clearance from her oncologist. P retired from his current practice. While gardening one day as they organized their property in preparation for the big holiday, P tripped and fell. The next day his walking was hesitant at times and on reflection Z reported some 'memory lapses', then

another fall, this time not thought to be a trip. Both Z and the family felt a medical check was necessary before the holiday so off to the doctor they went. Assessment and examination alerted the doctor and a referral to a neurologist to 'check all was well' was organized by the doctor. Their daughter J and son M accompanied P and Z to this appointment. Plans fell out the window as a devastating picture opened before them through the words 'brain tumor, no surgery, oncologist and radiotherapy' were heard. They went home to relay and digest this new crisis in their lives. Family togetherness was of the utmost importance following the fearful news prior to the next appointment especially with Z's recent experiences in the same department.

P, Z, their four daughters and son descended on the oncology department to discuss the future. P had radiation treatment daily for thirty treatments always supported by Z and one other member of their family.

I met with P and Z and family members during this treatment. Daughters, son, sons-in-law, and grandchildren arrived at various times during my visit to enable P and Z to introduce their special people in order for me to be aware of all involved in their turmoil.

P deteriorated slowly during the next few months but retained a lunch time ritual with family and loved relating his enjoyment of his lunch time 'PIE' from the local bakery as his opening words to me at each visit – 'what did I have for dinner today kids? ' A MINCE PIE! ' 'A

Nursing cares were needed when P's condition deteriorated and I increased my visits alongside the supportive care of the family members. M moved home putting his studies on hold to assist his mum with P's day and night care. Family came and went spending their own special time with P, sharing meals, supporting Z, discussing school and fun moments and dancing practices. P's interest in his waking moments related to all the family as he prepared them for his impending death. M shared his thesis work and P encouraged him to explore thoughts as they sat together that would enable his completion of this work in the future.

P died eleven months after I met him and his family. His funeral was a celebration of his life, his life with Z their family sons-in-law and grandchildren and although saddened by the finality of death they expressed how during his illness he had been preparing them for a

future without him. P will remain alive for his family and they will not fear future deaths. They will remember the creative engaging moments from personal experience that will empower them in their future relationships.

The treasures created and collected during this time will be positioned in the special place that is important for each individual.

The third narrative is related to bring contrast and not judgment to the palliative care experiences of my practice. This story relates my perception and reflections.

B was a 69-year-old Maori lady with a husband and four children still living. Her husband and daughter cared for her at home with the assistance of the local palliative care and Hospice nurses until her symptoms increased and assessment necessitated admission to the local hospice. The family then stayed with her in the Hospice.

Symptom management was achieved within days of admission and discharge home was discussed with B and her family. B chose to spend her last remaining days of life in the hospice spending time in the lounge

with her family depending on her energy levels. Her daughter provided her daily cares assisted by the nursing team as appropriate. As time progressed B moved to the double bedroom to allow family to visit together if they wished. This provided the room for everyone to share without being in each person's unique space. Family members visited in increased numbers in the last four days of B's life. Her husband, daughter and her husband, her two sons and their partners spent time together at the Hospice in the garden or in the family accommodation where they were enabled to share memories, meals, laughter and tears in this crisis time of their lives. The sharing empowered B's husband and daughter time to be in touch with their inner emotional feelings and explore supportive means appropriate for them following B's death. Family were all involved in their own special way one person digging the hospice garden, one cooking and B's personal cares still being given by her daughter. Grandchildren were not spoken of and neither was their handicapped son in care in the township. This son was brought to visit his mother the day before she died by a family member and his support care person. He had a meaningful place in the family prior to this event the family stated. He had lived at home until his early teens and then every Sunday since

he had gone into care had been spent with his parents and family until recently when his mother's health had deteriorated. He was 54 years old at this stage but still a child at heart. The Hospice team observed that there appeared to be no opportunity for him to be part of his family's grief journey and no opportunity for his special memories to be enhanced.

Following the funeral one son-in-law returned to the hospice with his two sons – B's grandchildren. This was their time to see and feel the room their grandmother had spent her last week, died in and the garden grounds and family areas where the family had spent their time together without the grandchildren. The grandchildren were aged between 18 and 22 years. In communicating with one grandson he expressed to me how important it had been to be part of the bereavement rituals of their family and to be in the last place where his grandmother had been alive. He said they planned on visiting family picnic areas the next day together to 'be family'. I asked him if he had seen and been with B. recently and he said he had been too busy so hadn't seen her or other extended family for some months – he lived less than three hours away. It may have been right for them during this crisis but I question the creative memories and strengthening family relationships along with future

ability of this child and his family to cope in times of crisis.

PALLIATIVE CARE

Palliative Care is defined by the World Health Organisation as total care for people who are dying. Total care affirms life as it acknowledges the dying process as a normal part of a life journey. Management of symptoms alongside the spiritual, psychological, emotional, social and physical needs of a patient acknowledges care of the whole person along with their symptom management in the transition phase of the dying process.

The New Zealand Palliative Care Strategy (2001) states “palliative care is the total care of people who are dying from active, progressive disease or other conditions when curative or disease- modifying treatment has come to an end” (p.2).

Palliative care is not an easily defined time for patients. Many professionals describe this time as a moving between treatment and palliation, or treatment from cure to symptom management at this time for the patient. The important ingredient in joining the two phases is hope. The importance of quality of life alongside hope is the reality that is palliative care. Pain, fatigue, nausea,

vomiting, breathlessness, constipation must be dealt with first. This relates to opportunities that will enable the patient to build coping strategies that will allow them to relate as a family unit during the palliative phase, the grieving stage and for future close experiences with dying relatives.

Communication bridges questions patients ask relating to their future as it opens the door to explore and link their journey to the family especially the children in the family.

Cultural and traditional practises in a person's family are what they bring to this phase of their journey together and the memories are what the family carry forward from the lived experience to the many and varied challenges to come in their lives.

The New Zealand Palliative Care Strategy includes a long-term vision for care of the dying patient and their family or whanau in their life alongside the care delivered by the health professional.

Pollard, Cairns and Rosenthal (1999) state it is the "heightened awareness of the prospect of death" (p.16)

that is the motivation that empowers our patients to invite us to walk with them and their families or whanau as they search to understand their transition from life to death.

Aranda (2001) states the “genuine regard and friendship” (p.182) between a patient and their nurse creates that trusting caring moment through communication that is the essence of palliative care. My experiences show children are often not included as they are frequently moved away from the closeness of the palliative patient’s room and sat quietly in the lounge with the television for company while adult family members converse together. This is an opportunity for the nurse to “value the difference they made for the patient and family” Aranda (2001, p.182) as they strive to bring all together to share, engage and relate.

Honest communication, friendship, respect, trust and quality become part of the whole experience for the patient, family, children and hospice team.

McClement, Chochinov, Hack, Kristjanson and Harlos (2004) wrote of the importance of research in palliative care to look at and explore dignity one of the basic

needs in the delivery of this essential care, that is care of the dying patient and their whole family. Care and dignity relate to the perception the patient has that impinges on external factors, quality and interaction within their value system and belief of what dignity is for them.

Factors relating to stress, the ability to cope, attitudes and behaviours, challenges and fears of dependant children will impinge and affirm the value of the unique lived life of every person within a palliative care service.

Saunders (1990) suggests children have an important role within the multi-disciplinary care team when their parent or grandparent is dying and during the post death ritual planning. Being empowered to share feelings in a creative way opens the gate to engaging in open relationships with family members and increases protection, support, acknowledgement and communication for the child with the care team. In the struggle to maintain a degree of control children can creatively breakdown barriers and empower all in the team to communicate effectively.

Fallon and O'Neil (1998) and Sheldon (1998) suggest the research shows effective communication, books, play materials and creative opportunities that engage all family members with the patient are a means of exploring and sharing in special moments of time. The moments I call sacred or tender for both the adult and child that is the essence of care for the patient in palliative care.

Saunders (1990) supports this creative means of interaction by stating "play and drawing in particular, helps children act out their emotions" (p.79) and when this is apparent control of inner feelings is possible. I have observed patients and their families sharing together in creative drawing moments - exploring anxiety, fears, feelings and opportunities for laughter and tears. This is the essence or heart of palliative care and grief work in the twenty-first century although it has not always been seen as important in previous centuries.

HISTORICAL FACTORS.

Lindsay (1996) writes of the historical view of recognizing children in the grief journey of a family as being non-existent prior to the 1880's. This was due to no records prior to this date. First written records, he suggests, of acknowledgment of children's health and welfare needs stems from this time. Families lived within villages with extended family living nearby. They took up the parenting role supported by church institutions in providing care and support following the death of a child's parent.

In the 19th century death was part of life for family. Death occurred at home, the work place or in lesser numbers at the hospital. During my search I found no written reports relating to assistance, support or changes to family and their needs following illness or death in families. I felt this related to the culture of this century.

The 20th century brought the welfare service with some improvements in education and health and the rights of the child to have these services until the age of 16 years. Children in the 1950's were told of a family member's death then sent or left with extended family or

neighbors during the funeral ritual. The first and most common experiences of death for the writer came while attending the local church school. Part of the school ritual was of viewing the elderly religious sister in her coffin in the chapel or attending parishioners funerals to join with prayers and singing especially when the deceased had minimal family and a larger congregation was thought to be needed to fill the church. When my paternal grandmother died we were taken to my uncles to see her in the coffin and then expected to play with cousins met only twice prior to this occasion. I remember my grandfather, aunt, uncle and father standing by the clothesline discussing the funeral and what would happen to my grandfather in the future while we were playing in the yard. I can't remember where the spouses of the family member's were at this stage but in hindsight they possibly were making sandwiches and cups of tea for the visitors inside. On the day of the funeral my brother, sister and two cousins were left with a maternal aunt to be minded. I was nine years old. I don't remember any form of communication regarding Grandma's death the following the day. I remember my aunt and mother cleaning the house. Memory pieces were not given to our family. It was work or school the

next day. This was normal practice in our family in the 1950's.

Lindsay (1996) and Rathbone (1996) write of the 1990's attachment theory of Bowlby's acknowledging the uniqueness of each individual as they form an attachment with another individual for support, imitation and communication from this supportive person for survival. The theory is based on trust as the most important component of growth. Rathbone (1996) took this idea further and explored acknowledgment of the inner feelings of a person and encouragement of them to imitate another through expression as a means of normalizing to assist in reflective patterns of grief in childhood. Hallam and Vine (1996) suggest the "unique nature of the individual child's grief" (p.51) experience follows the close relating that equates with Bowlby's attachment theory.

Society treats death and dying as a taboo subject in the 21st century. The person dying is usually behind closed doors in the hospital with a high level of technological input as part of the person's life until death occurs. The opportunity to not show our feelings becomes imperative in this situation and the ignoring of this spiritual

dimension of our inner self is the normal portrayal to the surrounding people. Intellectual acknowledgment and physical reactions over take spiritual and emotional responses and the result is a breakdown in our coping ability. This increase in anxiety and depression reduces our human expression of feelings and relating in future life crisis.

This can impede the grief experience and halt or delay the commencement of the healing journey for both adults and children. The hospice palliative care specialty in health encourages anticipatory grief in order to acknowledge and express feelings, communicate moments of intimacy and commence the adjustment journey of life with the person who is dying.

In the 21st century creating time to be with a person before death provides the opportunity to create memories for a child that they can then live with and call upon, explore, and imitate in future attachments with their special people. The living dying culture of my family allowed my father time with his children, grand children and great-grandchild. This is Bowlby's attachment theory in reality. Following L's week at the Hospice for symptom management he went home to eat, play, relate, sleep, and be with his family. The 'being

with family' is the memory time building that has cemented the family together. Family memory building occurred as L involved all in his daily routine. L controlled it all from the grand-child helping cut a toe nail with sand paper and wire cutters, to the garage painting under close supervision and meal times with 18 people present regularly and up to 25 some nights when extended family arrived to share in the evenings activities. Age restrictions were absent. All were there from the one-year-old to the ninety two-year-old as they desired. He over saw the card games played, the photos shared and music played along with the laughter and tears shared together as L conducted his last waltz.

This is the essence of caring or what Watson (1999) refers to as the relating of soul in our lived moments to restore wholeness to the family. Uren (2004) calls this a "celebration of life's possibilities" (p. 11).

Ensor, in his oral presentation at the Genesis Oncology Breakfast Session in May 2004 spoke of perceptions of "a good death" for patients in the hospice palliative care service as relating to a reconciled peace spent at home in the company of children and grandchildren. This was the ultimate goal for most people. He spoke of the

difference of a death in hospital when children visit for a few moments, or in some instances only able to see the patient who is their mother or grandmother from a distance. This experience removes choice and control from the patient, family or whanau and removes opportunities for children to be a part of the cultural rituals and traditions that belong to their family. Closed doors and technology in the management of symptoms give control to health professionals he said and take it away from patients their families or whanau increasing anxiety, non-coping mechanisms and the reduced ability to relate in similar experiences in future times.

Stokes, Wyer and Crossby (1997) literature research relates to how children cope in grief situations following a death in the family especially with creative ways to draw out feelings and deep seated emotional issues. They believed this affected the children's integration in future relationships and their social interactions within groups. Age, sex and socio-economic influences were investigated through this literature review and although this was a post death review I propose that by using art therapy in similar ways before the death of a family member similar results would occur. Stokes et al. (1997) states "the efficacy of using group art therapy"

(p.180) in research is important. Creative activities used in a personal grief journey reach deep within a person. Communication, story telling, sculpture, candlelight and balloons brought children and adults together to explore regressive behavioral changes common in grief experiences. The normalizing of emotions experienced through the sharing benefit both the child and adult and their relationships. Emotional reactions stemming from these experiences affect the child throughout life and need addressing in a positive open manner to prevent the child's imagination from being stretched beyond their coping ability to create inner turmoil.

EXPLORING PSYCHOLOGICAL EFFECTS

Long term human reactions to loss through death have been explored in psychological and psychiatric health as an important factor in presenting stories of people experiencing long-term anxiety and depressive disorders. The last words spoken in a dying moment are etched into the memory for the family to be revisited at successive deaths in adulthood. Lamers (1999) wrote, “early childhood experiences of separation and loss set a pattern for the way adults respond to loss” (p.22).

Compas, Worsham, Epping-Jordan, Grant, Mireault, Howell and Malcarne (1994) confirm through their research increases in psychological anxiety and stress in families when one member is given a diagnosis of cancer. This research related to families with dependent children. Interestingly they reported pre-adolescence children with the same sex parents having the diagnosis as having even higher anxiety and stress symptoms than a control group of children. The parent’s cancer was of the extent that at diagnosis they were deemed palliative. The research reported the children stating their anxiety and behavioral changes as being low. This

contrasted to the parents in their reporting of changes in their children. The researchers explained this in terms of the children protecting themselves as a means of reducing stress further in order to be seen in a “socially desirable light” (p.513). The research reported “the clinical significance of the findings” (p.513) presented anxiety and depressive symptoms as “evident in greater” (p.513) proportions than expected. This indicated support service interventions for children would be beneficial in a supportive group or when the moment for supportive communication was possible. This research indicates that the assessment of the family dynamics might be quite complex. Nursing interventions would need to be managed through incredibly carefully negotiated conversations with all involved. This is an art that takes time to develop as an individual let alone in the teams that offer palliative care through New Zealand.

The creating of moments either at home or on special outings are the memory building occasions Cook (1996) speaks of that assist in building our self-esteem. This is one of the important ingredients in psychological response in human's – the building or creation of memory to assist with coping in the life journey. Building trusting moments, playful times and creative

opportunities all provide the supportive blanket for children during the painful moments in their parent's illness.

Black and Young (1995) suggest several relating factors of anticipation in preparing for the death of a parent or grandparent. The child's level of understanding is the first factor to be addressed along with how the death will be for the person dying, the changes anticipated in their body and the time of day. All will need to be assessed in an effort to help "normalize the experience" (p.230) for the children. The prime benefit they suggest from this will relate to psychological and psychiatric illness reduction in later life. By building mechanisms to help cope, communicate openly, sharing in family ritual and through relevant children's literature many themes can be included such as pets, rainbows, plants and butterflies that will become a part of recall for the child in the future. They stated no educational research had proceeded their writing that evaluated the benefits of this idea although I believe practice of health professionals does confirm this in 2004 as it enables children to have acceptable and definite safe practices to address inner turmoil. Worden (1996) would say this reduces misconceptions by answering queries and questions

with respect to enable normalization of the experience. He states “children need information that is clear and comprehensible” (p.140) as well as “lack of information can make a child feel anxious and less important” (p.141).

Stommel and Kingry (1991) suggest children are being given or accepting tasks of greater responsibility than would be expected for their age when a parent is dying. They state the children sometimes provide an emotional relationship that will enable both the sick and the caring parent to cope with their tasks and their dying fears. This report looked at the parents or caregiver needs and not the children's. I question the long-term psychological effects for the children in situations similar to those reported in this study. The age of the children was not clarified but was cited as between ten to nineteen years and no information regarding psychological effects, support or communication were given leading to an incomplete report in this data.

Worden's (1996) research showed informing children of a family member's illness was not common practice and usually only occurred close to death. The ability to cope in a positive way occurred when children had been

informed at the time of the palliative phase of the illness. He went on to say grief reactions related to the children's "personal experience, thoughts and feelings associated with the death" (p. 11) and were effective in facilitating the adaptation to the loss for the child. He confirmed this when he wrote the "course and outcome of the bereavement is the pre-death relationship of the child with the deceased parent" (p.76-77). This related to the degree of attachment, dependency, age and sex of the child and the gender of the parent with the illness.

Dowdney (2000) confirms from his research that depression, dysthymia difficult sleep patterns, and dysphoria lowered mood symptoms in the first year post death manifest as emotional and behavioral changes that affect social relationships in children. Minimal studies had been conducted at that stage in the anticipatory grief phase Dowdney (2000) stated.

I found more evidence in the work of Siegel, Karus and Raveis (1996). Their research showed the high potential for psychological distress six to twelve months post death reported by both the children and adult caregiver. They stated that with anticipatory death "the opportunity for parents to gradually prepare the children for the

death and for the children to emotionally rehearse the loss" (p.449) benefited and lowered the level of distress in children.

Kubler Ross presenting a lecture at the Christchurch Town Hall in 1989 and Worden and Rapheal at the Fourth International Grief and Bereavement Conference in Sweden in 1999 spoke of missed opportunities and life pattern changes that caused grief reactions to children. These could be anger, rage or humor. By addressing reactions in a creative manner the child receives the benefits they require to deal with their emotions.

In writing of children's grief and death experiences Worden (1983) suggests the importance of communicating early and providing opportunities to explore according to age and comprehension what dying and death are to the child.

Junge (1985) states one way to achieve this is through making a book. She writes "perhaps it's most benefit to the family being it's preventive mental health function " (p.4) and this "reaction to any crisis is strongly influenced by past and present life experiences, ego

strengths and coping mechanisms” (p.4). Families working together draw out experiences through photos, drawing, story, poems or collage to create their living document. All relate together and react according to their cognitive ability in this sharing to make sense of their hurts, explore experiences and defuse fears within memory. Through this creative means a glimmer of hope can become a point of contact in the healing and as we search our memory bank of past experiences we can become enlightened and empowered in all we share together. Thoughts, feelings, actions and ways we express emotional turmoil can assist family members and ourselves in times of inner turmoil.

I believe through my experiences in practice that the creating of ritual to build memory is one of the most important experiences for the parent, grandparent and child.

BUILDING MEMORIES THROUGH RITUAL

Memory is often said to be a living part of us. Memory contains experiences, sensations, thoughts and knowledge that are unique to the relationship with the dying person. Through relating with patients, family or whānau and their children in my practice as a specialist palliative care nurse I too have built memories of my practice world and have purposely reflected on these memories. I have come to recognize that there is a specific process or way in which I can make suggestions to people about what they can create for the future with the person while they are alive. In my practice setting we have the opportunity to create the special moments for others to relate and build memories in their unique way.

We have identified that memories come through the moment to moment sharing, touching, showing, playing, making and noticing that occurs in the tender talk within the living moment. We use the term 'tender talk' to identify what occurs alone or with another person through stories, suggestions and explanations that can enable the person to extend their memory from the moments spent with their special person. The term used

by Cook (1996) is a gathering time, which suggests time with a person is the gathering time to collect the memories.

For L's family a special relating occurred at meal times when family gathered together around the table to share as they built up a picture of the days activities. The times the teacher had acknowledged their presented work, people seen at the swimming pool, L's visitors during the day, and the doctor and nurses suggestions for his care. These tender stories became the memories that were retold when extended family visited and added to the stories as they joined in the card games, music, TV news and the 'just being' moments.

P's special times were with the children as they sat around drawing pictures and writing stories to him. These moments he shared with Z later in the day to assist Z with building her memories that would be drawn upon in the lonely times in years to come for her.

Other authors have suggested music and art in the form of photos to concretize these memories. The visual impact of music Lamers (1999) suggests recalls moments previously shared and brings a closeness, a

feeling of being wrapped within the cloak of security as the tender moment is recalled in times of need.

Kelley (1999) brings another dimension to the cloak when he states “art offer(s) families a way to create special memories and conversations during the dying process and a way to remember and grieve during bereavement (p. 141).

The photos L shared along with his life experiences overseas during his wartime journey portrayed the many facets of his life only glimpsed previously by his children. Grandchildren were grasping for these untold stories of little known places they only dreamed they would glimpse in future years. When this opportunity arises they will recall L’s stories and relive his being in them.

Cook (1996) writes of the need to create time together. My experiences show for some families this will always be possible whereas for other families a gentle nudge may be needed to empower a spouse, partner, grandchild or spiritual director to create the moment for the person to express in a creative manner as they share their stories.

Creating through drawing, painting, poetry or sculpture digs deep into the unconscious and overcomes what cannot always be expressed in words. Rathbone (1996) confirms this method of expression when writing “encouragement to be creative ... is particularly relevant when everyone is having problems in expression” (p. 24). Children can be the catalysts alongside therapists and health professionals in opening doors for adults to put aside their inhibitions and explore or just be with their memories as they relive them. Previously lived fears, anxieties, hurts, angers, joys, love and peaceful life giving memories surface when the need for them arises. Edelman (1995) supports this when she said that writing arising from within a person brings strength and empowerment to them as it connects with their previously formed memories with the deceased person. This brings strength to our living.

“I am fooling only myself when I say my mother exists now only in the photograph on my bulletin board or in the outline of my hand or the armful of memories I still hold tight. She lives on beneath everything I do. Her presence influenced who I was, and her absence influences who I am. Our lives are shaped as

much by those who leave us as they are by those who stay. Loss is our legacy. Insight is our gift. Memory is our guide”

Edelman (1995, p. 283).

CREATIVE ART THERAPIES

Art therapy is a way of searching for the “spiritual dimension of health care” (p.38) to find “meaning and purpose in life especially in the midst of suffering” Robinson (2004, p.32). It is a way whereby it becomes possible to enter that special place deep within or an experience that is “greater than self” to find “a sense of meaning” (p.32) in the individual persons unique life.

This is a means to explore and express for ourselves, sometimes enhanced by another, the hurts, sufferings, anxieties and exhilaration deep within to gain “self expression and growth” Robinson (2004, p.33).

This is expressed in the following exemplar which shows how it can occur spontaneously as well as in a planned session.

One night a young man whose wife had died six months previously was attending a bereavement group and asked if I could visit with his two daughters aged four and six to talk with them. As I sat on the floor they told me through their art, music, dancing, dolls and leggo construction of their ‘mummy’. How she had done their hair, the lunches she had made and the things they missed most without their mummy present. Then with

crayons they sat drawing while their father and I shared coffee and he talked. The youngest daughter crawled up on to my knee and told me through her drawing of the sadness inside. She had drawn their family with a hole where mummy had been. She talked of her smell, sitting on her knee for a cuddle and the way she had smiled when she looked at her.

On reflection this was an attempt at art therapy – one way to reach deep within another to explore their inner feelings.

The practice of art therapy started back in the 1940's in the United Kingdom in the psychiatric hospital wards as a way of reaching patients inner thoughts and trying to find a medium for them to express them. By 1997 this form of practice had grown to enable patients to find the glimmer of hope. The cloak of protection through music, art, drama, imagery, poetry and other creative means would reach deep within to trigger memory and allow them to express their tender moments.

Nicholas and Lister (1999) define art therapy as a “human service profession that utilizes art media, images, the creative process and patient client responses to the created products as reflections of an

individuals development, abilities, personality, interests, concerns and conflicts” (p.101).

Boyes (1997) in writing of children’s presence with dying family members suggests open communication answers the inner questions and draws out the feelings around the creative moments. Constructions, modeling, games, drawing and music are some ways of providing the medium through which cultural rituals can be lived. Traditional family rituals enable memory and life treasures of the child and family to be explored and reclaimed from the treasured tender moments that belong to them alone.

Robinson (2004) confirms and supports the need for the exploration and recording of anxieties, anger, love, hope and fears experienced in life as “the way in which people find meaning and purpose in life, especially in the midst of suffering, (p.32). This can provide a medium that enables a person to be in touch with that inner place through their creative means. By “putting thoughts and feelings into words and images can help clients come to terms with situations that feel insurmountable” Robinson (2004, p.36). He suggests this is a “vehicle for increasing understanding and a channel for the

expression of his or her deepest unspoken concerns” (p.36).

This supports experiences of people sharing in bereavement groups being given a sheet of paper and drawing what comes to the fore for them. When they are given the opportunity to speak to their creations, drawings, paper mashie, collage or collections the deepest concerns have surfaced and been expressed by them on paper. Children can explore further the connection between their dreams and conscious thoughts and these can be expressed through the images created in art. Nicholas and Lister (1999) confirm this in their statement “expressing powerful feelings on paper, the child is able to start to bring order out of chaos. Both the process of doing the art and the final product are inherently therapeutic, creating an organization and permanence to inner experience that is the crux of child art therapy (p.102).

Kelley (1999) supports this in his statement “the arts assist patients, families and staff to understand the whole of their lives, as well as the profound journey towards death that they share” (p.139) and that “the

reality of the evolving art work is a product of growth and discovery” (p.139).

Connell (1998) stated art therapy “can help a person find a contact with their inner world more quickly and deeply than many other means” (p.12) and “in life where social interaction usually means talking, to be able to communicate through silent empathy is a rare experience” (p. 19).

To reach an inner space we need to create time, use materials, ideas and find the space alone to explore, create and interact by digging deep within our self, without pressure from another. We need to trust the experience.

A song, a word, a person, an animal, a touch or smell can be a “vehicle for increasing understanding and a channel for the expression of unspeakable concerns” Connell (1998, p.75) suggests, and when working with family members this is apparent.

Connell (1998) writes that British Art Therapists believe their involvement is necessary in the healing process. I acknowledge their wisdom and knowledge of practice

and suggest for children facing crisis in grief the experience and opportunity to explore and create memorable experiences through art is possible without professional therapists to facilitate in the expression of inner thoughts to paper. By creating trusting, playful experiences creative responses will follow when working with children and in hospice palliative care settings this must be the first step.

Music is one creative form that touches the dying person, their family or whanau. For many adults and children it creates a visual memory that can be recalled easily in moments of stress, anxiety, fear, fun, joy, family ritual or other times of sharing and communicating.

Communication and expression of feelings are enhanced by music suggests Lamers (1999). I confirm this as I recall a piece of music my father always had played during family celebrations. It became a family ritual at gatherings over many years prior to his illness and brings childhood warmth each time it is heard by our family still. Grandchildren ask for 'granddad's music' as it is referred to in the family and sit with thoughtful smiles as they recall the words and actions from the first time they had heard the music. A cloak of closeness to the

dying person is the way Lamers (1999) refers to such recall.

Furth (1988) wrote of the value of drawing whereby symbols meet in our unconscious space and reflect the relationship between this space and the given moment in our time. The drawing connects the person to the space, place and circumstances in an impromptu manner through the symbols in the drawing. Color, texture and symbols are some of the materials that Furth (1988) speaks of as “road signs” (p.102) unique to the drawer as they express meaning in the particular moment of time explored. Monsters, witches, boggy-men, birds, flowers, houses and people are all symbolic road signs.

Skylight (1992) leaflet printed to assisting grieving children and the Season Program run for children suffering grief experiences suggest the use of a memory book as a way of creating living experiences with children in this crisis moment in their lives. Both provide materials and assistance for children and young people facing change, grief, or loss in their life. The season program uses group work to achieve a peaceful space for the child. Skylight states “the memory book allows its

owner to have ready access to important memories of someone who is no longer with them. It is 'personal' and 'not intended to look professional' as it provides a precious, created, woven interaction of art therapy that connects the maker in their grief journey.

The written words confirm this:

“through the expressive nature of art, dance, music and drama children are free to express verbally and non-verbally the repressed and difficult feelings associated with their bereavement” (p. 472) as they “have a need for media that enable(s) them to express what feels impossible to explore verbally given their limited vocabulary”

Kirk & McManus (2002, p.472).

CONCLUSION

During the transition from life to death for a person the uniqueness of the essence of caring relates to the moment of trust between the patient and family. This connection enables a sharing in the memory building time that is a humbling experience for the palliative care nurse. Through caring we are able to support people to have the courage to live as they desire and do as they wish at this stage of their life journey.

Through narrative I have unfolded the cloak that surrounds the moment to moment experience bringing to reality the experiences and unique sharing within my family and through the fictionalized narratives of patients and their families and whanau. As I reflected on the tender talk within the unique moments the significance of the being in relating to another became clearer. The special moments etched within my memory reflected experiences unique to me and similar to those related within the fictionalized narrative although it also exposed differences in families in the New Zealand culture in the twenty first century. The importance of memory relating to created moments shared within our family enabled me to explore ways I felt may reduce prolonged grief

experiences identified by myself when working in palliative care and bereavement support areas.

Palliative care teams support dying patients with their expertise in symptom management and terminal care and support for family or whanau.

People are enhanced and empowered to be open to the creative experience that will open their mind to build communication pathways between them. The need to reach deep within without pressure enables us to explore the memories that have been our life living experiences in the past.

History relates stories of experiences in the 18th and 19th centuries of dying people being nursed at home and families coping the best way they could with support from the expended family and local village people. The daily routine of the family was unchanged with the traditional rituals being a village affair. Children were part of the village ritual and their life was expected to continue as it had before the death.

I related how there was minimal change to this practice as late as the 1950's in our family when the children were removed from the death bed scenario and funeral

ritual when a family member died and were cared for by extended family while adult family members completed the rituals.

Emotions were not acknowledged or explored until the 1980's when psychologists started to believe that the exclusion of children from dying family increased the risk of mental health symptoms in later life. Anxiety and depressive disorders were thought to stem from the repression of feelings and emotions during previous death experiences.

Children are catalysts in opening the door to enable their parents, aunts, uncles, brother and sisters and friends to express themselves. To explore through the eyes of a child opens a door to enable another to search for their experience in their memory wall, or web of life, and build new memories through the experiences that will be their strength in the years to come.

To find understanding, awareness through touch and smell, a listening ear, music, silence and fear in the connecting moment will empower one to have recall in future times of need.

How we support family members, especially children, during a parent or grandparents dying will provide opportunities for relating, sharing and acknowledging feelings, through tears and laughter.

Creative means form unique and lasting memorials. Memory books, boxes to hold treasure, sculptures to enable the expression of creative touch, poetry or narrative to state inner feelings, photos to provide instant recall, puppets and drama provide expressive art. All emotionally can enhance and bring together patients, their family or whanau and especially their children to initiate open communication in a loving way.

All creative art opens the door for exploration of unknown fears and new experiences that allow people to discover a new freedom from emotions deep within. With courage and endurance it will permit the person to overcome the emotional roller coaster ride they shared with their parent or grandparent who they loved with all their heart.

Attachments formed during our life are the memories that make our protective cloak we can then wear when loneliness, crisis and emotional turmoil overwhelm us.

Creative art therapy grounds children in a unique way as it enables them to cope with change through a medium by which they explore and communicate with another person. Their creations during these experiences lead to integration of memory and healing embraced by sad moments within the cloak of protection in their life journey and their place within their unique cultural family history.

I believe the Hospice Palliative Care service I am employed in will endeavor to empower, enhance and explore unique ways to engage children in to create living memories for them. This will reduce mental health disorders in future adults. I want to be a part of this extension of our service in the years to come as I know children will engage their parents and friends to be a part of this form of creative art therapy. To be part of the being of spirituality for one person will mean I have achieved through this research.

I dream of an area for children with all means of creative material being available for them to create their memorial of their special person. I hope to collect together the materials and put them in a box to be taken in the car boot for children to use in their homes with

their parents or in the corner of the family room which will become the central and special area for the creating narrative, memorials, writing poems or painting as children share in the living, dying and being times within their families.

Through empowering and encouraging alongside evidence of practice the specialized team within our unique hospice palliative care service will become involved and active in this area that will open the door to enriched personal and professional memories.

Death apparently is the only sure thing in life. The hospice palliative care multidisciplinary team assists the dying person to squeeze every last moment from their life in their own way and leave lasting memory within their family and children.

“There is always one moment in childhood
when the door opens and lets the future in”.

The Power and the Glory.

(Henry) Graham Greene, Claremont (1995, p.8).

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