



**PLAYING AT THE THRESHOLD:
THE ROLE OF THE THERAPEUTIC CLOWN IN THE CARE OF CHILDREN
WITH LIFE-THREATENING ILLNESSES AND THEIR FAMILIES**

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There are references to two clown characters in this article, both of them created by the author of this piece. Posy was the therapeutic clown for the Hematology/Oncology Program at SickKids for nine years. Flora is currently the therapeutic clown for the Palliative and Bereavement Care Service, at SickKids in Toronto.

What is a Therapeutic Clown?

The clown may be an unexpected presence in the health care setting, but historically and culturally, from medieval jesters to the sacred clowns of many First Nations peoples, clowns have been associated with healing and the well-being of society.

The Canadian Association of Therapeutic Clowns/L'Association Canadienne des clowns thérapeutiques (www.therapeuticclowns.ca) defines a therapeutic clown as a clown who is specifically trained to work in the health care field. The therapeutic clown is committed to being a regular presence in the health care setting, collaborates routinely with other members of the health care team, engages in on-going training and development, and receives appropriate remuneration for the work. All CATC/ACCT members agree to abide by the association's Statement of Principles and Code of Ethics. Therapeutic clowns hold true to the central ideas of clowning, but at the same time function as health care professionals. Their make-up is generally light, and their costumes are designed to be practical and appropriate to the settings in which they work. Therapeutic clowns are sensitive to the reactions of those around them, and are skilled at engaging children and their families. They are responsible and accountable for their actions, and may be required to offer feedback on their interactions in meetings, at rounds, and more formally through progress notes.

When the therapeutic clown works and plays in the area of pediatric palliative care – whether in a hospital, hospice, or home setting – her understanding of her work, the role she plays in the care of the child and family, her sensitivity and compassion, and indeed her sense of accountability and responsibility are heightened. Interactions with children, siblings, and other family members can be both intense and delicate. The support of a multidisciplinary team is essential.

The landscape of pediatric palliative care appropriately includes an emphasis on the child and family's quality of life. The nature of this care is holistic, encompassing physical, psychological, social, and spiritual wellbeing (Liben, 2008). The health care team must be responsive to each family's needs and to the unique nature of each family's journey with their child's life-threatening condition and ultimate death.

What Do Parents Want?

In an article by Beverly Antle, et al. (2005), "*Pediatric Palliative Care: What do Parents Want?*" the authors summarize the results of three qualitative studies done at SickKids in Toronto with families of life-threatened children. Four key themes emerged: respect for the child and family, greater co-ordination of services, normalization of the child's activities, and a focus on hope. The study participants suggested that energies could be better directed toward enhancing a child's quality of life and happiness rather than



trying to sort out information and services provided by different health care professionals. One parent commented “He just wants to be a seven-year-old-kid and do armspits and all that stuff.” As one member of the multidisciplinary team that cares for these families, the therapeutic clown can offer interludes of play and laughter. She encourages in the child a sense of mastery and works to build a supportive relationship with the child and family.

Supportive Relationships

In many ways, the clown is well-suited to be a companion for the child on a journey with a life-threatening illness. The famous clown Grock (in Cline, 1983) described himself as being “as sensitive as a mimosa plant,” with all his self-protective armor peeled away (p. 46). The vulnerability of the clown engages the child and helps to build a supportive relationship. Because the clown is an unexpected presence in the hospital, as out-of-place in the healthcare setting as the child, they can become allies. When the clown visits the child in the community, the tables are turned, but the clown is still not on home ground. Barbara Sourkes (1995) suggests that the establishment of “a secure therapeutic alliance” (p. 11) is an intervention in and of itself. This special alliance or relationship is frequently understood and appreciated by families. Once, to the delight of all the listeners in the playroom, a petite three-year-old greeted me by saying, “Hello, little Posy, Posy,” even though I am obviously adult-sized. When – out of character – I attended the visitation of a child I had known for several years, I was introduced by his father as “a personal friend” of his son. Another parent commented as I arrived for her son’s funeral: “He always let you in.”

The therapeutic clown also works to build relationships with siblings, often creating opportunities for interactions with their brother or sister who is ill. Two sisters of a two-year old with a brain tumor who can no longer take part in the play, still love to sing to him the familiar songs Flora sang to him earlier on. With puppets on our hands, we sing about elephants, frogs, and teddies on spider webs, and when it is time for small hand-paint tattoos, he is always included. His picture – a heart, a small apple, or a sailboat – is always painted by his eight-year-old sister. The therapeutic clown becomes adept at balancing the needs of healthy siblings with the needs of the child who is the patient. It is not unusual for the clown to look up and see that all members of the family, including teenage siblings and parents, have been drawn into the space of the play. Sometimes, the play has all the hallmarks of an impromptu party. The therapeutic clown may visit the home on several occasions after the death of a child to maintain her relationship with siblings who have come to know her well. Flora also has a website (www.florac clown.ca) so that siblings can stay in touch if they wish.

Mastery and Empowerment

Added to the clown’s vulnerability and openness is a certain inability to cope with the details of everyday life resulting in confusion and ineptness as well as a good measure of humor. Clown historian John Townsen (1976) suggests that “the clown’s ability to evoke feelings of superiority in the spectator plays a hidden role in all clowning” (p. 206). The therapeutic clown works to empower children, offering choices and encouraging a sense of mastery at a time when there may be many limitations in their lives. It could be said that the therapeutic clown exists in a state of potential, waiting to be completed by the child, so that each child has the clown most suited to his or her needs. A small child can give advice about hand-washing and managing paper-towels, or tell Flora that a bubble she can’t find has simply popped. A child can initiate Flora into the world of dinosaurs or transformers. Children delight in putting Flora to sleep with the tinkling notes of her magical music box, waiting only for the moment when they can shout and see her wake up with a start – a giggle-inducing piece of play which is repeated many times. The therapeutic clown is at the service of the child and is a most amenable playmate as the play unfolds in satisfying ways. However, the therapeutic clown must be skilled in keeping the play and the players safe. She must be aware of lines and other hospital equipment, as well as of the needs of other staff as they care for the child. After one game of hide-and-seek, involving my clown Posy and a four-year-old child hiding in the bed curtains while his father loudly stomped around looking for them, the child burst out into the room yelling, “Power Rangers, attack.” Then turning to me, he added, “Bring my IV, Posy.”



Children will often take care of their clown friend, painting a small picture on her hand, retrieving forgotten toys, or helping Flora fit things back into the toy box. One child liked to do up the buttons on my coat as I left her home after a visit. An over-excitable Bunny puppet was the occasion for a child to express her need to offer care as well as receive it. In a relationship that developed over many months, this ten-year-old girl taught Bunny how to breathe to calm herself, and rocked Bunny to sleep at the end of each visit. Bunny sometimes helped to distract her during painful dressing changes. In fact, Bunny became such an important part of the play that Flora the clown all but vanished; I was simply there to bring Bunny to life.

Play and Humor

The therapeutic clown is in her person a most vivid invitation to play. After she asks permission and steps over the threshold into a hospital room, a living room, or a bedroom, anything can happen.

Play is both a right of the child – Article 31 of the United Nations Convention on the Rights of the Child - and a normal activity of childhood. Play in health care environments is “an essential element in reducing the degree of threat perceived by children in the new and unfamiliar surroundings” (Gaynard, 1998, p. 248). Sourkes (1995) comments that play enables the seriously ill child to “reenter” childhood (p. 5).

The therapeutic clown is not a play therapist but properly engages in therapeutic play. Christina Brown (2001) defines therapeutic play as “play that facilitates expression, coping, and mastery. It addresses the child’s need to express feelings, solve problems, and work through or resolve conflicts or distress” (p. 250). Brown continues: “Generally speaking, play that is predominantly child directed and open ended and that invites the child’s verbal or non-verbal expression of thoughts and emotions may be considered therapeutic” (p. 258).

The play space has been called the magic circle (Huizinga, 1955). This space can be created inside the larger space of the hospital or home. It may be an intimate space, small enough for two or it may be big enough to encompass every member of a family and whole worlds of the imagination. Because play is a framed event with a beginning and an ending (Sutton-Smith, 1984), each playtime can have a satisfying shape – whether it lasts for an hour or just for a few moments. Information acquisition and learning have been described as a breathing in (Jaffke, 1996). For the child, and indeed for the family, illness and hospitalization are a huge in-breath. Free play offers opportunities for breathing out. Perhaps most importantly, play space is safe space. In the play space, the child can perhaps find what Sourkes (1995) describes as “a ‘safe place’ within the storm” (p.81). The players make the rules. Together, as O. Fred Donaldson (1993) says, they become, in this meeting place, “a new ‘we’” (p.32).

The play space is a generous one, open to whatever comes its way. A bubble play with a child on the hematology/oncology unit prompted a father to say: “You know what the photographers say? Life’s a bubble. Picture it before it explodes.” Sometimes the play offers a parent the opportunity to express the inexpressible. A little wind-up bear that had to be tapped on the head to get it moving occasioned this comment from the mother of a nine-year-old girl. “If I tapped you on the head, would you go on?”

With play comes much needed humor and lightness. The child and family’s situation is extraordinary, but there is time and space for some appropriate levity. Within the safe play space and in the context of a supportive relationship with a therapeutic clown, children can express their own humor. A three-year-old child in the ICU, on a ventilator, with a tracheotomy, took the end of Flora’s slinky and with a glint in his eye turned it into a steering wheel. When Flora laughed, a passing health care worker said: “He’s making the clown laugh!” For parents, seeing a smile on the face of their child can be beyond value, and never forgotten. Many years after I had worked with a child who died of cancer when she was four, I met her mother at a hospital event. She introduced me to her colleague as the person who was responsible for her daughter’s last smile.



The Play Conversation

Play between a child and a therapeutic clown often follows predictable and comforting paths and takes on all the familiarity of a revisited conversation. Children look for familiar toys in a clown's kit, and request the same game over and over. "You know what I like painted on my face," said one small boy. As the child becomes less able to play, the therapeutic clown takes on the role of facilitator helping the play to continue as long as the child wishes. A six-year-old girl, not long before her death, communicated to Flora every detail of the hand-paint design of hearts and flowers she wanted, even though she could only indicate "yes" or "no" with her eyes. As Hilden and Tobin (2003) point out: "With their natural tendency to live in the present and their ability to cherish play and other pleasant experiences, dying children often astound the adults around them" (p. 8).

Conclusion

The therapeutic clown travels with a small kit of bubbles, puppets, toys and games, but it is equally important that she have a repertoire of songs, stories, and skills. Working in the context of family-centered care, she moves from singing to babies, to toddler play; from shared imaginative storytelling, to hanging out with teens. Often the entire family gathers around when a clown visits. The therapeutic clown working in the area of pediatric palliative care must also understand that the quality of her presence is as important as the diversions she offers. In some situations, it is all she can offer.

The therapeutic clown, especially one who can move between hospital and home, can become a welcome and trusted presence for children and their families who are receiving palliative care. The clown, by her very nature, "enhances life" (Hoyle, 1989). She honors the right of each child to play as long as he or she is able. She offers opportunities for creative self-expression, empowering play and gentle humor that include the child, siblings, and other family members. During these times of respite from the concerns of illness, videos and photographs are taken, and memories are created. For the therapeutic clown it is a privilege to witness the journey of children and families as they face the realities of life-threatening illness and impending death. And a privilege to contribute to a child's "good day."

"Posy the clown dropped by and she and James had a ball together.
So it was a good day."

Syd Birrell. *Ya Can't Let Cancer Ruin Your Day: The James Emails*.

I wish to express my gratitude to my colleagues, the members of the Palliative and Bereavement Care Service at SickKids in Toronto.

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