

## Case Studies in Palliative Care

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Palliative Care is a concept of care that includes not only people who are dying but are very ill. Based on Ira Byock's book: "The Best Care Possible" [1], this model was used to describe two complex, non-Academic Center Cases. The model focuses on asking the patient and family what they would like to happen in this medical situation, and then draw together every Medical Service involved in the patient's complicated care.

Patient A was a retired New England Professor, who had a chronic and worsening hereditary peripheral neuropathy. He was met on the surgical service after he had developed deep Stage 4 ulcers in his heels and over the proximal head of his fibulae, following a fracture and repair of his left hip. His ulcers were taken care of as an outpatient, and then admitted him for antibiotic care and work up of his poor vascular condition. He was determined to have iliac occlusion bilaterally. He also developed a non-infected urinary problem. The decision was made to use the palliative care model with round table discussion of all interested parties, when resources at our small critical-access hospital became sparse and treatments challenged.

The Critical Care Team sent a nurse, a physician and social worker to talk to the patient and each family member. They used the written records and face-to-face as well as telephone discussions with the neurologist, internist, general and vascular surgeons, orthopedic and urological surgeons. A conference with the family, the patient and clinicians ensued moderated by the palliative care physician. The decision was to send the patient to a distant tertiary care hospital in the city where his pregnant daughter lived. They moved there for a year. One leg was amputated and prosthesis successfully fitted. Both Patient A and his grandson graduated to walking about the same time. He was kept in touch for many years. The family has consistently praised this model of patient-centered decision making.

Patient B is I. I was an active General Surgeon, married with grown up children, living in a rural community. Very suddenly, I became anemic and feverish and was diagnosed with Acute Myeloid Leukemia. I was immediately transferred to the nearest Cancer Center and underwent early acute diagnostics and treatment. My family hurriedly convened from distant travels. My husband was unable to cope. Through the first 24 hours, I felt helpless. Then I remembered Patient A and I called on my colleague in palliative care for help. Immediately I was aware that this was the correct decision. I felt a great load was lifted. The pastoral care, social workers and clinicians were very quick to ask the questions needed. The hematology team worked hard to keep me alive through the next year and three stem cell transplants. The first two transplants failed and I was left with complete neutropenia, until the third successful one. The palliative care team was concerned with how the family was coping, how I felt and offered massage, reiki, music, art and eventually poetry interventions [2].

What I found was the symptoms of nausea, anxiety, pain and fever became more easily managed with the inclusion of creative arts [2]. Each day, one member of the Palliative Care Team came to see me. They often timed these visits to coincide with visits from my family visits to help me face the unpleasant treatments and diagnostic tests. I filled out a card prior to and following an intervention by the arts and massage therapists. The data was collected and shared with the administration of the Tertiary Cancer Care Center. I was only one of many on the list of each therapist.

When I returned home, I was able to use the poetry and painting option to deal with many negative emotions. I kept in touch, not only with the clinicians, on outpatient visits, but also with all of the art therapists and on occasion with the physician and social worker on the palliative care team. My husband certainly also benefited from the support. His despair was alleviated by including him. Counseling would have been isolating and inappropriate. The care given to my family was essential.

### Discussion

These models are paid for by a mixture of grant money and insurance payments. Ongoing therapeutic success was measured by the popularity of the program and the improvement in the scores applied to nausea, anxiety and pain, after the interventions. It is believed that they are cost effective, because the treatment becomes more acceptable and successful.

Ongoing outpatient contact was made with the Palliative Care Team and the art therapists. General wellbeing and full family support appeared possible with these models.

After recovery, creative arts program would be added into every hospital palliative care team and to get a procedural code attached to each intervention, so that insurance companies will be able to support the care and motivation of critically ill patients helping them reduce pain, eat food and feel less anxious most certainly creating a better state for noxious treatments to work. This must include a code for family care as well.

The success for the patient through these two examples was clearly demonstrated. The family role is also supported. Most patients have a support system which will flounder if not included in the care and expectations of the patient. The situation without specifically including them is more typical. For many less complex situations, where patients are admitted, treated and discharged home with comprehensive instructions, a family member is a bonus, not a necessity. In a situation without family or network, the palliative care team has to engage the person's community. In the palliative care model it is described, each patient could not have benefited to this extent/ without the family and intervention of the palliative care team. The numbers of medical interventions, specialists, therapists and general daily interactions were overwhelming and disheartening but these were paced by the palliative care teams and the massage and art therapists. The "pacing" drew an openness and increased acceptance from the patient and family, so that the perceived symptoms, teased out, were fully addressed and "treated". The clinical teams were always interacting with the palliative

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care teams, making for long days for each, but the outcome in these two cases was successful.

The combination of all interested parties from clinicians to art therapists, with active inclusion of the family, or any support, was life saving.

#### References

1. The Best Care Possible by Ira Byock (2012).
2. [http://patients.dartmouth-hitchcock.org/arts/creative\\_arts\\_program.html](http://patients.dartmouth-hitchcock.org/arts/creative_arts_program.html)