

Tuesday October 28, 2008 David Morrison - Speaking Notes only.

Challenge question: While the patient and family are recognized within the hospice palliative care community as members of the collaborative care team, the level of involvement varies widely. How do hospice palliative care programs and services respond to this? What are the challenges and benefits? Do patients and families want this role? This Challenge Panel will address the concept of the patient and family as the 'unit of care' and how this role may be changing in today's health care environment.

Slide 1. First of all, I wish to thank our team! Secondly, I wish to recognize and thank Julie Cole, Medical Librarian at the QEH, who assists me so much in subject and document retrieval.

Slide 2. The WHO calls palliative care "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness." As suggested in the challenge question, I can say that our team attempts to respond fully to that definition.

Slide 3. Most physicians have traditionally concentrated on only trying to cure patients. Many may still be stuck there. In a peer reviewed paper published almost forty years ago, I can remember saying the obvious - 'that many physicians saw the lack of a cure as a failure, and that should a doctor live so long, she would see all her patients die.' Treatments for alleviation of symptoms were viewed as secondary and possibly seen as inviting addiction and unwanted side effects. At the same time, we are moving away from the GP overseer who knew all of the family.

Slide 4. The focus on a patient's quality of life has increased greatly over the past twenty years. The percent of hospitals offering a palliative care program has increased significantly, perhaps as high as 55% . The question being raised this morning refers to the increased inclusion of the family, and family members, in the journey. One of the challenges is to measure or ascertain what family dynamics existed before illness, and what behaviours are peculiar to the family member's illness. Sometimes we think we should be addressing dysfunctions which have been there for years (or decades).

A relatively recent development is the concept of a dedicated team that is entirely geared toward palliative treatment. Ours is called an integrated palliative care team, reflecting the participation of various disciplines.

Slide 5. Effective palliative care provides a way to address both physical and psychological distress. For the patient, psychosocial distress includes total pain, (or suffering), a concept associated with Dame Cecily Saunders, and now widely used. Dealing with total pain involves a broad range of concerns, starting with treating physical symptoms such as pain, nausea and breathlessness.

Palliative care teams have become very skillful in prescribing drugs for physical symptoms, and have been instrumental in showing how drugs such as morphine can be used safely while maintaining a patient's full faculties and function. However, when a patient exhibits a physiological symptom, there are often psychological, social, or spiritual symptoms as well. The interdisciplinary team, which often includes a social worker/ counsellor and a spiritual care clinician/ counsellor (or a trained pastoral care chaplain), can play a significant role in assisting patient and family cope with these symptoms, rather than depending on the medical/pharmacological interventions alone. Much of the work involves family dynamics, with knowledge tools to help young children of patients, through to young adults who get bent out of shape with their parent's disease (usually cancer).

Slide 6. The joy and the possible danger in palliative care team collaboration is that professional boundaries may blur. Professional artistry as well as technical competence guides a sensitive team's approach, including much of the intervention being based on a grounded clinical experience. With team trust and interdependence, a compassionate relating has an incredible benefit for the patient and family. Quite frankly, a role one team member cannot do, another can do in excellence, and vice-versa... especially when family dynamics come into play.

A palliative care patient, and the patient's family, have concerns surrounding pain; but also carry fears of the future, the impact of the myriad of losses symbolized (such as the loss of independence), concerns about family, and being a financial and care burden.

Some patients will respond to psychological or spiritual concerns. Others have not reached that point. Yet, it is important to have some type of assessment, and there are various models.

Whether or not one uses an assessment of caregivers' burden is not too prevalent (I think) although they are available. It may be important to use a formal or informal assessment to measure the family caregivers's burnout or family psychological distress during the end-of-life journey. Even without a specific instrument, our team assesses the family dynamics.

Most hospice palliative care is directed to cancer patients. But we don't stop there. For example, advanced COPD should equally require team interventions. I can think of nothing more threatening than incapacitating dyspnea. Families also experience a decline in psychosocial and physical functioning. As a recent summary report stated: "models should embrace the needs of those who witness and suffer from the relentless struggle of patients to cope with worsening dyspnea. The broad range of associated fears and anxieties are so prevalent in the advanced stages of COPD." JPC 24:1 Spring 2008. 53.

Slide 7. Because it is in the domain of every team member, and since it is becoming widely recognized, we mention the role of spirituality in the palliative journey. Not to be confused with religious practice (which is important for many, especially as a vehicle for spirituality) there are certain characteristics which we recognize... although this differs from practice to practice.

Slide 8. In part, "spirituality is an integral component of healing. It is a source of strength in the presence of distress. It is at the heart of our well-being. It enriches all aspects of our life: physical, mental, emotional and community."

Slide 9. Symptoms of spiritual distress include anxiety, depression, anger, hopelessness, loss, guilt, resentment, conflict, regret, powerlessness. [From our Cancer Centre Brochure] These affects are coloured by the unit of care ... usually a family.

Slide 10. Our team has become a symbol for best practice, and has a role in being an innovative model for palliative care in hospital settings, community, home, cancer treatment centre. Expertise from each of its team members complements the work of physicians and other health care workers. It also stands alone in its own practice. It has a responsibility for interprofessional education to other health care professionals. The challenge question surrounds the situation of having families as active members of collaborative care if they wish to be. Fortunately, even when palliative patients are under the care of acute care staff, there is a recognized linkage to our team. If necessary, we meet with the whole family and the responsible physician.

Slide 11. The quality of care and the professional teamwork have led to evidence-based observations and reflections on improved patient and family outcomes. Through its continuity of care continuum, there is an increased QoL, smoother transitions, less duplication, shorter hospital stays, increased emotional, social and spiritual support, better pharmaceutical and nutritional inputs/controls. The team's effect has also allowed for improved pain and treatment management. Care provided is allowing patients to remain at home longer, also to die at home with dignity if they wish. There has to be a significant positive cost-offset.

Slide 12. But there are always placement pressures. And the "spoken desire" to have the patient back with family is not always the reality.... from both sides.

Slide 13. From many quarters. Sometimes we work too well!

Slide 14. This interdisciplinary team, meeting weekly for patient presentations, consists of two home care nurses, social worker, pharmacist, two physicians including the director of the Palliative Care Unit, spiritual care clinician, nurse practitioner, two coordinators for hospice care

(respite and companion visitors; bereavement follow-up), music therapist, palliative nursing director, secretary. The team, at its best, takes patient/family involvement from theory to action. One example is music therapy, where the music therapist can create a “legacy CD” reflecting the patient and is a gift for the family.

The team celebrates a mutual trust and positive working relationships. I celebrate this with you today ... as many of you celebrate your own palliative care teams. In those settings where a palliative care model is effective, the patient and family as the unit of care is not only ‘working,’ it is the model for today’s health care environment.

Slide 15. And finally – who heals the healers? – we’re called to heal one another – through our teams.

David Morrison, PhD, FRSA  
The Strathmor Group  
[www.strathmor.com](http://www.strathmor.com)