ROCHESTER REGIONAL HEALTH
Rochester General Hospital

A Tale of Two Patients

The Role of the Palliative Team in Defragmenting Care in the Inpatient Setting

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Objectives

1. Understanding the challenges of a fragmented Health Care system and how these challenges impact the care and symptom burden of individual patients.

2. Improving appreciation for the role of an Interdisciplinary Palliative Team in "Defragmenting" care in order to achieve patient and family centered Goals of Care

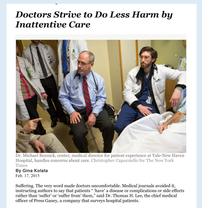
3. Utilizing the concept of Total PAIN in treating complex critically ill patients on a Palliative Care (PC) Consult service.

Background

Fragmentation of health care delivery has been a challenge to hospital staff and patients for many years now. Fragmentation of care can occur for many patients and often involves, or can worsen, patient suffering. The concept of suffering due to structural processes in the health care system and not just a result of the disease process has been a national focus of care delivery.

Fragmented care as a cause of patient and family suffering

Hastings Center Report 2006



The Stress of Fragmented Care
NY Times 2015

Ref: Hastings Center Special Report, 2006.
Kolata, G (2/15/2015) Doctors Strive to do less Harm by Inattentive Care, NYT.
Lee, TH, Perspective: The Word That Shall Not be Spoken N Engl J Med 2013; 369:1777-1779

Proposal:

Address Fragmented Care with Total Pain

We propose that by using the concept of Total PAIN and applying it to patients whose health care has been fragmented in the process of long term stays, suffering can be reduced for both End of Life and chronically ill patients. By utilizing the interdisciplinary Palliative Care team, solutions can be found to both the frustration and the suffering of Fragmented Care.

Ref: http://www.growthhouse.org/stanford/modules.html PP2: Pain. Stanford Faculty Development Center End of Life Care curriculum.

Total **PAIN**

In Total PAIN, suffering is assessed in four key areas:

P:Physical Pain,

A:Affective or emotional pain,

I: Interpersonal pain and

N: Non acceptance or spiritual pain.

The interdisciplinary PC team is ideally suited to assess and manage this complex condition.

Patient 1

Fragmented Care

74 yr old RHF, had TVR with multiple post op complications

LOS	168 Days	MD Notes (#)	295
Providers (Total)	**273**	Total MDs (#)	75
Hospitalists (#)	18	Residents (#)	7
Author Types	20	APPs Involved (#)	26
Consult Services	14		
Notes #)	**943**		

Defragmenting Care

Palliative Care Consult at 91 Days for Bladder Pain

PC Notes	61
Chaplain Notes	17

Defragmenting using Total PAIN

Role of Spiritual Care

Multiple visits by the PC Physician, NP & Chaplain

Multispecialty meeting organized for updating an angry family in order to review all medical options.

Additional family meetings later held to establish a unified goal.

Acceptance of reality of disease trajectory as approaching end of life.

In this case the Palliative Care Chaplain was key to reducing the distress experienced by both the patient and his family in order to move care forward.

The spiritual aspect of total pain was key to the defragmenting process.

Distress occurs when a patient or family member experiences unmet needs.

Illness and hospitalization stress people at a multitude of various levels: physical, emotional, social, mental, and spiritual.

Our patient experienced distress in many areas

Abandonment
"My family and friends don't come around as often."

Anger
"I've had every operation, done every procedure, but I'm still not getting better."

Hopelessness
"I'm never going to leave this hospital."

Existential
"What is the point of my suffering?"

Guilt/shame
"I am letting God down if I don't fight to live."

Isolation
"My wife won't let me give up."

What happened?

1. A final family meeting with several medical specialists lead to the understanding that the patient had no further benefit from remaining in the hospital and he was unable to participate in or benefit from physical therapy.

2. One of the local home health agencies specializing in hospice was invited in to evaluate the patient and design a plan to allow the patient to go home (his main goal).

3. The patient was discharged on hospital day 168 which was the day of his wedding anniversary.

4. He died at home peacefully approximately 5 days later.

Patient 2

Fragmented Care

65 yr old with mediastinal large B Cell lymphoma.

LOS	73 Days	MD Notes (#)	128
Providers (Total)	**221**	Total MDs (#)	60
Hospitalists (#)	13	Residents (#)	12
Author Types	22	APPs Involved (#)	21
Consult Services	11		
Notes (#)	**650**		

Defragmenting Care

Palliative Care Consult at 55 Days for PEG Decision

PC Notes	13
Chaplain Notes	7

Defragmenting using Total PAIN

Role of the Social Worker

1. Family meetings initiated using a SW in the MICU: There was Defensive body language and "Inappropriate" language from family members.

2. Rapport-building: once there was a relationship with the SW, Palliative care could be brought in to deal with symptom management. The family rejected discussion of goals, ACP or spiritual care support. Rapport was built through understanding the Psychosocial History of the patient and his family.

What happened?

The "forgotten step-children of medical care" non pain symptom management:

Anxiety – SSRI titration and frequent contact with the daughter by phone

Insomnia – sleep hygiene and Trazodone

Constipation – a Bowel regimen

Fatigue: low dose steroids

The Palliative Care team supported pursuit of PEG placement. Pt was discharged to acute rehab on D 73 and eventually returned home, continuing to use the PEG for nutritional support.

Conclusion:

Patient care can be fragmented in many ways: multiple providers from multiple services, multiple locations within the hospital, multiple symptoms including emotional, interpersonal and spiritual needs as well as physical pain, even fragmentation of patient and family goals given the stressful situations involved. By using the simple model of Total PAIN, and addressing all aspects of pain in these areas, as well as utilizing the unique approach of the Interdisciplinary Palliative Care Team, suffering due to structural processes is reduced and patients find an ultimate resolution to what seems like an endless hospitalization.