

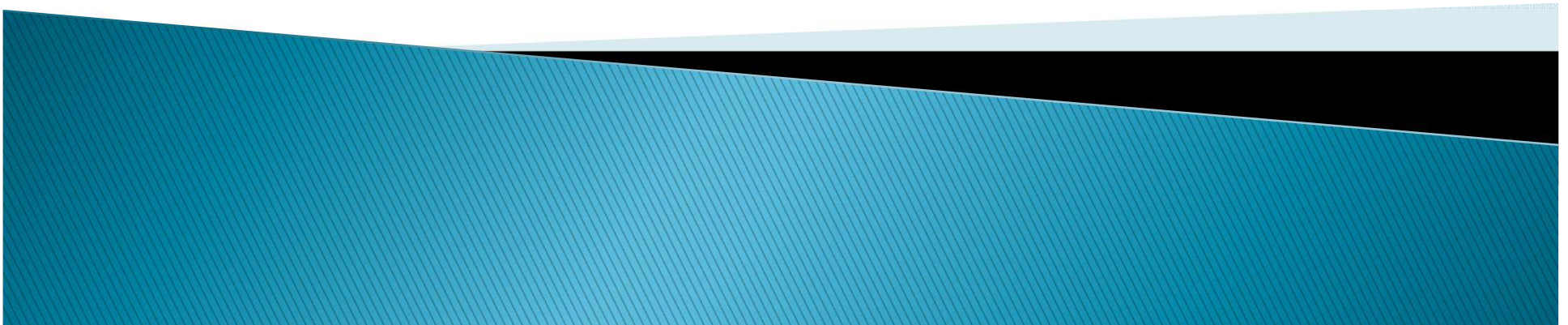
Limited Permission for Psychiatric Consultation

Two End of Life Cases

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Consultation with end of life in view

- ▶ The consultation process is typically time limited
- ▶ For end of life cases there often are no clear time demarcations as the patient progressively loses footing
- ▶ Consultation in these situations requires extraordinary sensitivity and availability by consultant and may need to be extended as the patient's condition deteriorates



Cases

- ▶ Two cases taken from sample of 23 complex EOL patients at a long term, acute care hospital (LTAC)
- ▶ Both patients fighting infections, ventilator dependent, anticipating end of life
- ▶ Both desperate to remain alive until convinced someone would carry on with loved ones
- ▶ The patient in both cases felt ongoing consultation was key to a successful life ending
- ▶ In effect the consultation, as it developed, was personally meaningful for both the referring physicians and the patient



The Patient's Role

- ▶ As Mr. L. became increasingly miserable wondering how long he could carry on he pleaded with the consultant to join him in meeting more often, including joint meetings with his priest
- ▶ For Ms. S. it was the tight grip of her hands each time the consultant visited that communicated her desperation to have him remain with her
- ▶ *In both cases the consultant made repeated requests to hospital administration that the consultation be extended, and was repeatedly rebuffed



Mr. L.

81 years old

- ▶ Devoted husband and father of 5
- ▶ Observant Catholic family
- ▶ Retired teacher of literature
- ▶ “Pillar” of the community



Mr. L. – Medical (1)

Cardiac

- Original: 1988, first MI → Cardiac history ultimately includes systolic congestive heart failure and ischemic cardiomyopathy + cardiac cachexia
- Recent: [25 years later] 7/31/13, Admitted UCSF (University of California San Francisco, Medical Center) for acute heart failure and placement of LVAD (left ventricular assist device). At this point had end-stage cardiomyopathy



Mr. L. - Medical (2)

Pulmonary

- Following LVAD placement could not be weaned from ventilator
 - 8/11/13 [1 mo later], required a tracheostomy to support breathing
- Very depressed, with severe sleep problems.



Mr. L. Medical (3)

Other medical issues:

- Dysphagia from previous stroke (gastric feeding tube implanted)
- Bilateral phrenic nerve/diaphragmatic palsy*
- GI symptoms: diarrhea and GERD, both difficult to control

[*Note: Bilateral diaphragmatic paralysis: The treatment of bilateral diaphragmatic paralysis mainly depends on the etiology and severity of the paralysis. Invasive ventilation was historically the main treatment for patients who developed respiratory failure as a result of bilateral diaphragmatic paralysis.]



Mr. L. Medical (4)

Hospitalizations During my Contact with him

- November 2013 [5 mo after discharged from university medical center], Admitted to KRH (Kentfield Rehabilitation Long Term Acute Care Hospital) for (unsuccessful) ventilator weaning and rehabilitation after placement of left ventricular assist device.
- February 19, 2014 [4 mo later], readmitted to KRH after 5 day hospital stay at UCSF for PEG (gastrostomy) placement. Initially anticoagulation problems developed, ICU monitoring required



Mr. L. – Psychiatric Consultation

- ▶ Psychiatric consultation initiated by hospital physician [4 days after admission to KRH] 2/23/14 because of Mr. L's distress. Follow-up initiated soon thereafter and was increased to approximately one visit every other week until death in May 2015 [15 mo after first admission to KRH]
- ▶ Wife summarizes his pre-existing capabilities as "remarkably competent." Both patient and wife find his disablement and suffering "intolerable"
- ▶ In a note he sent on 4/9/14 [2 months after first consultation] (he can't speak) he says that he wants to be "optimistic about the future" but finds it hard and "needs to talk regularly to a doctor"



Consultations with Mr. L.

[Second consultation occurred on April 2014, 2 months after initial consultation]

Excerpts from dialogues from my consultations with Mr. L. follow (The speaker is Mr. L). We need to converse by writing because of his tracheostomy. Note the constant regeneration of hope against his inconsistency of mood and despair



Dialogues with Mr. L.

- ▶ 5/25/14 [third consultation one month after second] "I want to live and am hopeful. However, I don't want any extraordinary life support measures."
- ▶ 1/15/15 Wife calls and requests more visits from me . Mr. L. wants to initiate EOI planning. He is feeling tormented, clings to me
- ▶ 1/20/15 Ambivalently – with some hope – thinks about recovery
- ▶ 2/1/15 Says he has learned that there is, "No possibility of going home." We discuss priests who could administer last rites.
- ▶ 2/26/15 "Day to day routines getting harder." I think about the kids (sobs) and how they need to be a part of this process." Catholicism moves to the center of his thinking after this conversation
- ▶ 4/22/15 Decides he wants to die at home and forgo life support measures [increased depression and despondency] On the next day he becomes somnolent during day.
- ▶ 4/26/15 Talk with wife: "We want to bring Dick home to die, even with the understanding that it will be difficult to provide the a level of care his condition requires. [Family crisis. My intervention is carried out in association with a priest]



The Consultation – Summary

- ▶ Over several months of my returning every other week Mr. L. progressively revealed his “need to live” in order to be present for his wife and children. Over time in spite of constant setbacks he is reassured by my promise that I will do what I can to see to it that his end of life wishes are carried out
- ▶ HOWEVER, hospital administration repeatedly rejects requests for additional visits after third consultation. Negotiating additional appointments with administration is arduous and visits often need to occur in my own time



SECOND PATIENT



Ms. S. – Stiff Man Syndrome

Mrs. S: 62 y/o with progressive gait disturbance for at least 8 months

- ▶ Aug 20, 2012 fell at home: Result: Severe lower back pain, unable to walk.
- ▶ Hospitalized Kentfield Rehabilitation Hospital (KRH). Treated with vertebroplasty
- ▶ Discharged Jan 14, 2013 (after 4 months). Dx included vertebral fractures with lower extremity paralysis, respiratory failure requiring ventilator and partially associated with pneumonitis, dysphagia.
- ▶ Readmission to KRH 7/15/13 (7 months later) for continued pain and attempted but unsuccessful ventilator weaning



Medical history and treatments at KRH

Differential Diagnostic Considerations:

- **Physiatry:** spinal stenosis
- **Neurology:** neuromuscular disorder “such as primary lateral sclerosis”
- Sent to Pacific Medical Center in San Francisco for further evaluation: diagnosed with ALS in spite of her atypical symptoms
- Final but tentative diagnosis: R/O Stiff Man Syndrome



Medical

Medical Summary on her admission [7/15/13] -

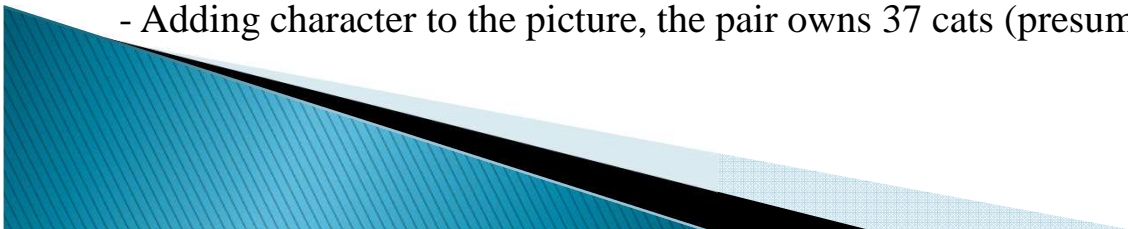
- Airway obstruction, spastic paralysis (now quadriplegic), lower extremity pain at times intolerable and in part consistent with unappreciated hip displacement
- Primary diagnosis remained unconfirmed
- Appropriate restorative efforts initiated including: attention to breathing, treating pneumonitis, attempts to relieve pain



Psychosocial

Family/living circumstances:

- Lives in a rural area in the California (central valley)
- Economically indigent, neither the patient nor husband employed
- Husband described by several health care professionals as "kind of crazy" i.e. "insufferably self centered and unable to truly care for or attend to wife" (but they were high school sweethearts and are apparently devoted to each other). He is described as "suing everything he can get his mind attached to" (e.g. he is a veteran and is suing the military). Further he owns guns and others suggest that he could possibly be dangerous.
- The couple has a developmentally disabled son in his mid twenties
- Adding character to the picture, the pair owns 37 cats (presumably leaving their home unsanitary).



Available care delivery options:

Current Treatment Dilemma

- ▶ Patient's Medical deterioration
- ▶ The family's financial resources are limited (Where to find financial support for the care she and her son and husband required?)
- ▶ Patient quickly running out of Medicare's convalescent care allotment



Medical and Psychosocial Possibilities for Patient

- ▶ There is no case manager
- ▶ **To partially address the patient's needs I appealed for and with great difficulty received limited permission to extend my consultation.**
- ▶ Very limited options for supported future care consists of hospice (but can the husband cope with the idea that his wife may be so close to death?), finding someone who can assist and guide the husband (a VA psychiatrist?), finding a community mental health advocate for the patient and to provide a liaison for help with the husband.
- ▶ **NEEDED:** A *plan*, in addition to someone who can help them execute it but likely to be difficult to implement given the husband's psychopathology.



Personal Reciprocity Between Patient and Physician

HER PART

- The patient hangs on to life at all cost because she felt (verbalizes) that her presence was the only hope for her husband and son.
- She believed that her single personal resource was myself, the psychiatric consultant.
- She looked forward to each visit from me (the consultant),
- Held my hand during the entire visit and seemed more hopeful after each visit.



Reciprocity Between Patient and Physician

MY PART

- I thought about her frequently throughout the week and found myself looking forward to each visit with some renewed hope.
- This case was presented to our medical discussion group. One physician member made the statement that the "easy stuff is the medical" and that we actually gravitate toward it because it is so much more manageable than the combined psychosocial and financial issues in cases like this



Reflections – Both Cases

- ▶ The relationship aspect of the consultation was critical in both cases. As a result of the extended consultations both patients could die with peace of mind since their most pressing needs were recognized and were being honored by consultant,
- ▶ HOWEVER: Hospital administration progressively withheld permission for continuation of each consultation, requiring me to go to the administration repeatedly for permission. I was also forced to provide consultations in my own time.

The consultation relationship in these and other similar cases went both ways

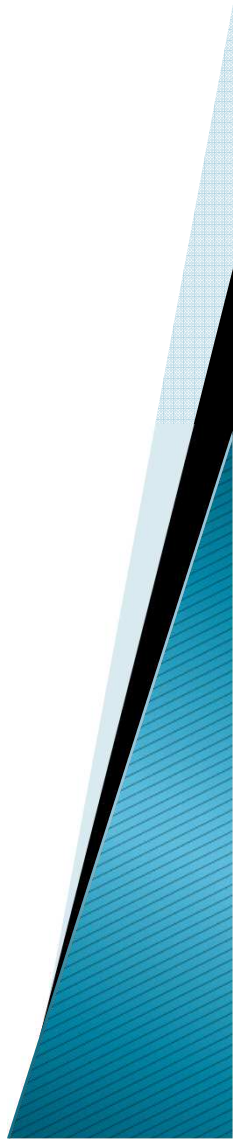
- ▶ With the physician's ongoing "presence" critical to engaging and maintaining the patients involvement, including by guiding the patients through, in these cases, end of life tasks
- ▶ But, in both cases the patient also engaged the consultant, creating a meaningful, ongoing relationship that was critical in enlisting the consultant's continued availability and advocacy



Reflections

Bilateral authenticity was central to success in both cases i.e. each patient believing that the consultant would remain available as long as he could and that he really cared, while each patient reached out personally to the consultant





Stiff Man Syndrome

Rare neurologic disorder unclear cause

Manifestations: progressive rigidity and stiffness primary affecting truncal muscles

Spasms and postural deformities, pain, impaired mobility

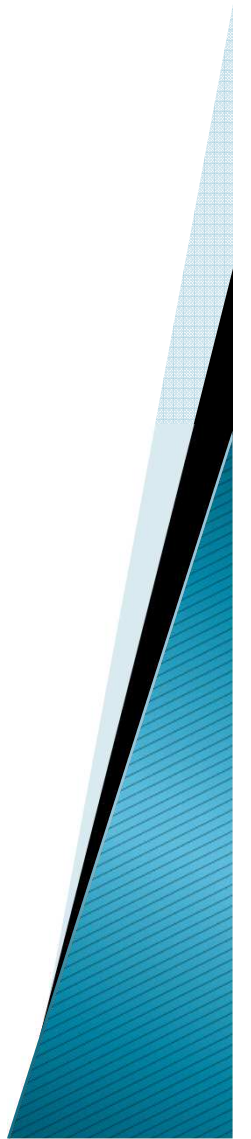
GAD antibodies common



Stiff Man Syndrome (2)

- ▶ Rx Benzos, also baclofen, IV immunoglobulins, rituximab
- ▶ Quality of life suffers, falls common. Progressively fatal (metabolic acidosis or autonomic crisis)





Relationship Centered Care (RCC*)

- ▶ All illness and treatment occurs within relationships
- ▶ In RCC all participants recognize importance of relationship with one another
- ▶ In RCC all interaction is seen as reciprocal
- ▶ In end of life cases interpersonal issues are heightened

▶ *Mary Beach and Thomas Inui Jan 2006 Journal of General Internal Medicine



[omit?] Mr. L. Medical (5)

On second admission, February 19, 2014, he was cognitively grossly intact. On ventilator with LVAD

- ▶ Continues to suffer from bilateral phrenic nerve palsy. Requires ventilator, likely secondary to “chronic illness and infections”

Prognosis for phrenic nerve palsy resolution uncertain, “greater than a year.” -- This news very distressing to Mr. L and his wife

