Conflicted Surrogate Syndrome: A Proposed New Diagnosis

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Florida Society for Post-Acute and Long-Term Care Medicine
October 14, 2016
In Remembrance of Samuel (Sam) Kidder
Objectives:

At the conclusion of this session, the participant will...

(1) Discuss whether or not a Conflicted Surrogate Syndrome should be recognized as a diagnostic entity by the long-term care and regulatory community
(2) List several reasons other than the well being of a nursing home resident for decisions and actions of a responsible party causing actual or potential harm for a LTC resident
(3) Review the characteristics of a pathological family system
(4) Discuss potential strategies to ameliorate or mitigate problems caused by the proposed Conflicted Surrogate Syndrome
Disclosure

One case tangentially mentions the off label use of propanolol for the treatment of benign familial tremor though the indication for a beta blocker in this case was primarily to Rx hypertension.

The discussion is historical and not intended to encourage the use of propanolol for any off label condition.
Case One
Case One

• Mrs. Jones is an 85 year old woman with a Hx of moderate dementia; MMSE 16/30; without decision making capacity
• She has a neurogenic bladder, indwelling foley catheter, Hx of colonization, Hx being treated for UTI due to having a UA with C&S greater than 100,000 CFU/ml of a multi-resistant organism
Case One cont’d

- She has a son that visits on weekends and receives calls from the Resident frequently at his job during the week.
- The calls that he receives during the week are usually complaints from the Resident regarding minor health complaints and occasionally complaints about the facility.
Case One cont’d

• Today as in the past, the son complains that the Resident has a bad smelling urine that looks cloudy and wants her assessed for a UTI

• The Resident has no other symptoms but wants to be assessed for a UTI because she does not want to become ill and need to go to the hospital
Case One cont’d

• When son is told by the nurse that the physician has diagnosed chronic bacteriuria and explains this condition, declining testing, he becomes very unhappy.

• As in the past, he raises his voice at the nurses, states that he will get another physician and states that if his mother becomes ill, the physician will be hearing from his attorney.
Case One cont’d

- At his next visit to the NH he tells the nurses that he is getting another physician for his mother and that he will be getting an attorney if his Mother becomes ill.
- He tells the nurses not to tell the physician.
Mental Capacity - Who Is the Decision Maker?

- Judgment
- Orientation
- Memory
- Abstract thinking
- Calculations
- Ability to negotiate/collaborate in one’s own best interest
- Able to persist in a decision (in absence of relevant new facts)
- Freedom from undue influence

JOMAC
Mental Capacity - Who Is the Decision Maker?

- Shared decision making (cultural versions)
- Proxy decision making variations
  - Texas Family Medical Decision Making Act
  - DPOA, Springing POA
  - Conservatorship
  - Guardianship
A Proposed Definition for Conflicted Surrogate Syndrome

A syndrome characterized by actual or potential negative outcomes of a LTC Resident due to social, psychological or psychiatric problems in a responsible party (RP), family member, or the family system.

A Proposed Definition

Unusual circumstance with pathology in an individual(s) who is (are) not the Attending Physician’s patient.

Not unprecedented though –

Folie a deux

Munchausen’s by proxy

Comports with view of disease within the family system ala Family Medicine
Possible Causes of Conflicted Surrogate Syndrome

• Guilt at placing loved one in institutional care
• Stereotypical attitudes toward LTC and staff
• Denial of Resident’s true condition, pre-terminal or terminal status
• “Squeaky wheel” tactics
• Psychiatric disease of the Responsible Party

Con’t
Possible Causes of Conflicted Surrogate Syndrome (con’t)

• Personality disorders of the responsible party
• “Setting the nursing facility up” for later malpractice litigation
• Pathologic family system
  – Victim/abuser issues
  – Resident triangulating family member(s) against NF staff
• Others?
Psychopathology Risk for Caregivers

• More likely to have depression and anxiety than age and sex-matched noncaregivers (Dura et al, 1991)

• Impaired immune response (Robinson-Whelen, Kiecolt-Glaser, Glaser, 2000)

• Higher levels of cortisol and stress hormone (Bauer et al., 2000)

• Caregivers who appraise caregiving as burdensome had a higher risk of mortality over a 4 year period (Schultz and Beach, 1999)
Psychological Interventions

• Caregivers seem more resistive to change (Knight, 2004)
  – May be related to nature of caregiving
  – Long-term commitment
  – Chronic stress rather than acute stress model
Stress and Coping Model

• Early research was based on help-seeking caregivers (Shultz et al., 1995)

• Later research focused on avoidant coping styles (Li, Seltzer, and Greenberg, 1999)
Family Systems

• Need to expand beyond the primary caregiver and the white, North-American-Western European culture
  – Latino family unit (Aranda and Knight, 1997)
  – Involvement of secondary and tertiary caregivers in African-American families (Dilworth-Anderson, Williams and Cooper, 1999)

• Prior relationship issues
• Reunions at time of caregiving
  – How were primary caregivers selected?
  – What are the family dynamics?
  – How to involve other caregivers in care and treatment?
Structural Family Theory

- Minuchin postulates that family interactions are regulated predictable patterns that determine how family members communicate and interrelate.
- That healthy families adapt while others become rigid or disorganized under stress.
- That family interactions are predictable, often passed from one generation to the next, relatively stable and resistant to change.
Characteristics of a Pathological Family System

• Enmeshment
• Isolation of family members from rest of society
• Lack of privacy within family
• Lack of generational boundaries
• Hyper-religiosity
• Rigidity
• Lack of conflict resolution
Approaches to Conflicted Surrogate Syndrome

- Recognition and documentation
- Open communications
- Team meetings
- Avoid 1 on 1 conversations (triangulation)
- Double check “facts”
- Avoid heroism

Cont’d
Approaches to Conflicted Surrogate Syndrome

- Avoid “copping out”
- Issues with the “hotline”, bureaucracy
- Clarify the problem/pathology and collaborate to address this, not the complaint of the Responsible Party
- Consider alternative person as responsible person, guardian, and/or involve APS
Lessons from the Literature

Family can be enlisted to be involved in care planning and participating in delivery.

– Treat as an insider, not as an outsider
– Decreases “shock” of institutionalization for resident and family
– Regulatory issues-caution:483.75(e)(4)


Janzen W; Long-term care for Older Adults. The Role of the Family. J Gerontol Nurs 2001 Feb;27(2):36-43
Recognizing CSS as a diagnostic entity could possibly:

• allow state surveyors to do an expedited review of complaints or blind complainant to the investigation

• improve likelihood of an individualized and therapeutic approach to solve the real problem

• thwart litigation
Where Do We Go From Here?

• Further case reports?
• Epidemiological study of frequency of CSS among all complaints?
• Studies of remedial approaches?
• New paradigm of diagnosis and treatment of the family unit, not the individual person?
Case Two

HPI:
- 91 y/o Caucasian female admitted to SNF after 3 day hospitalization for multiple falls
- Altered mental status
- Hx ASHD
- Hx MDD
- Severe benign familial tremor
- Physician adds mixed personality disorder
Case Two cont’d

• Meds: B12 monthly, Timolol, Senna, Amitriptyline, Alprazolam, Levetiracetam, Primidone

• Hx of Botulinum toxin injections for tremor, last with severe ADR

• MMSE 12/26, GDS 3/15
Case Two cont’d

- Propranolol substituted for timolol and up titration with serial objective measures of tremor
- Objective clinical improvement denied by Granddaughter (RP) and insistence on treatment with antipsychotic after home visit
- Non-constructive Resident/RP/MD visit
Case Two cont’d

• Additional Hx from Resident to nursing staff regarding home visit involving family confrontation concerning Resident’s deceased husband’s sexual abuse of daughters

• MD’s hypothesis of care demands as retaliation by family on Resident
REFERENCES:


Li WL, Seltzer MM, Greenberg LS. Change in depressive symptoms among daughter caregivers: An 18-month longitudinal study. Psychology and Aging 1999

Mace NL, Rabins PV The 36 Hour Day (3rd ed) Baltimore, MD: Johns Hopkins Press. 1999
Minuchin S. Families and family therapy. Cambridge, MA: Harvard University press, 1974


AMDA White Paper: The Role and Responsibilities of the Medical Director
Discussion

Interactive