The Family as the Unit of Care: Challenges & Rewards

Sarah Burton MacLeod, MD CCFP
&
Kim Crowe, BSW RSW
Tertiary Palliative Care Unit, Grey Nuns Community Hospital, Edmonton, Alberta
Disclosure

- We have no financial relationships to disclose.
Objectives

1) How to identify at-risk families.
2) Increase awareness of the tools and techniques that may be helpful, including the family conference.
3) Understanding how caring for these families can lead to counter transference, compassion fatigue and burnout.
Definitions

- Canadian Hospice Palliative Care Association
  - “A family is whoever the person says his or her family is.”

- World Health Organization
  - “An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness…”
Challenges that Families Face

- Caregiving
- Liaising with healthcare providers
- Decision making

Meanwhile…
  - Working through their own anticipatory grief
Family Systems Theory

- theory of human behavior that views the family as an emotional unit
- uses systems thinking to describe the complex interactions in the unit.
  - It is the nature of a family that its members are intensely connected emotionally
Family Systems

- Emotional interdependence evolved to promote cohesiveness and cooperation families require to protect, shelter, and feed their members.

- Heightened tension can intensify the processes that promote unity and teamwork leading to problems.
  - When family members get anxious, anxiety escalates & spreads.
  - As anxiety increases, the emotional connectedness of family members becomes more stressful than comforting. Eventually, one or more members feel overwhelmed, isolated, or out of control.
Family Systems: A Palliative Approach

- Palliative Care promotes the family to be whomever the patient identifies them to be
  - Relatives, partners, and friends

- Identifies “family” as the unit of care (Canadian Hospice Palliative Care Association)

- Death and dying should be perceived as a family event
  - Reorganizes family roles, requiring adjustment of all family members

Mehta et. al, 2009
Family Systems: A Palliative Approach

- Families contain and interact with many subsystems based on relationships
  - Sibling, spousal, parental

- A change with one of the members of the family will influence the entire system

- It is important to understand a family unit's boundaries
  - Will impact how open/closed the family is to working with healthcare providers
  - Will determine the level of impact a team will be able to have on the family

(Mehta et. al., 2009)
Resilience vs. Morbidity

- 18-35% have poor Resilience
- Characterized by:
  > Poor communication
  > Minimal teamwork
  > High levels of conflict
  > Indicate a higher risk of psychological comorbidities and “intense grief”

(Zaider & Kissane, 2009)
Identifying At-Risk Families

- Family Conferences

- Zaider & Kissane, 2009
  - Family Relationship Index
  - Psychosocial Assessment Tool
  - Distress Thermometer:
    - 0-10. “circle the number that best describes how much distress you have been experiencing in the past week including today”

- Family Inventory of Needs

- King & Quill, 2006
  - Family relational Checklist
Family Conferences

- Family Conferences well documented in ICU Literature

- Characteristics of the Palliative Care Family Conference
  - (Yennurajalingam, et. al, 2008)

- Effectiveness of Family Conferences in PCU
  - Looked at the effectiveness of the Family Conferences in Dublin
    - 31 family members
    - Family Inventory of Needs and Self Report Instrument
      - Showed increased confidence in dealing with issues raised, and more care needs met compared with prior
      - (Hannon, 2012)
Structure

- SPIKES
  - Most commonly used in Edmonton
  - See next slide

- VALUE
  - (Value family statements, Acknowledge emotions, Listen, Understand pt as a person, Elicit questions)

- ABCDE
  - (Advance prep, Build therapeutic relationship, Communicate well, Deal with reaction, Encourage emotion)

- Others
  - (Sharma & Dy, 2011)
SPIKES

- Set up interview
- Perception
- Invitation
- Knowledge
- Emotions (address with Empathy)
- Strategy and Summary

(Baile et. al., in Sharma & Dy 2011)
Rationale

- Shared problem solving
- Education
- Assessment of Family needs
- Function

- Why don’t we do this more?
  - Time
  - Cost
  - Availability
Cross Cultural Communication

Sharma & Dy, (2011)

“Integrated pattern of human knowledge, belief, and behavior…the customary beliefs, social forms, and material traits of a racial, religious, or social group and the set of shared attitudes, values, goals, and practices that characterizes an institution or organization.”
Using Interpreters

- Professional Interpreters are under utilized
- The use of professional interpreters (in ICU) is associated with:
  - Increased patient satisfaction
  - Fewer errors
  - Greater participation by relatives

Schenker, 2012
Compassion Fatigue & Burnout

- Compassion fatigue is the “cost of caring” for others in emotional distress. Figley, (1982)

- Burnout is a psychological term that refers to long-term exhaustion and diminished interest in work. Burnout has been assumed to result from chronic occupational stress. (Wikipedia)
Recent Trends

- Increased anger in the clinical setting (Philip, 2007)
- Younger patients
- Increased expectations regarding communication
- More well informed patients (Holst, 2009)
Counter-transference

- Staff may unconsciously associate with the patient or family experience.
Kim & Sarah-ism

- We always say...
  - “Know yourself”
  - “Read your reaction”
  - “Ask why?”
Strategies

- Prepare if possible & bring experienced staff with you.
- Take time to listen.
- Reconsider you’re approach
- Modify expectations
- Consider limit-setting
- Ensure the team is on the same page
- Avoid splitting
- Support team
- If needed, involve a independent broker

Philip, 2007; Maytal & Jackson, 2012; King & Quill, 2006
Advice for Teams

 “It’s not how you feel, but how you behave”
  › Maytal & Jackson

 “Between stimulus and response there is a space. In that space is our power to choose our response. In our response lies our growth and our freedom.”
  • Viktor Frankl
Special Mentions

- Hoping for a Miracle
  › (Widera, 2011)

- “Long-shot” Treatments
  › (Wiessman, 2010)
References


- Hannon, B., O'Reilly, V., Bennett, K., Breen, K., & Lawlor, P. G. (2012). Meeting the family: Measuring effectiveness of family meetings in a specialist inpatient palliative care unit. *Palliative & Supportive Care, 10*(1), 43-49.

References


References


References


