Title
Top Tips for Dealing with Family Stresses in Palliative Care

Eileen Reilly
Senior Social Worker
Beaumont Hospital Palliative Care Study Day
28/9/2017

Subtitle

Working with ‘Family Difficulties’ and ‘Difficult Families’

Who are the family?

Definition

- “All those in a loving relationship with the person who is dying, the people who can be counted on to provide care and support, regardless of blood or legal ties”.
- **Lattanzi-Licht et al. (1998) from Kovacs et al. Family Centred Care Coldwiz**

Prevalence of Family Stress

- Conflict within a family and between families and staff is common
- Research suggests higher prevalence of conflict between adult children of patient than between spouses. (26% v's 13%)
- Studies have found as high as 40% incidence of serious conflict between family members, with sibling conflict being especially common.
- Prevalence of anger ranged from 9-18% in cancer pts and their families in various descriptive studies.
- Australian survey found that 62% doctors had been verbally abused in the previous 12 months in Palliative care settings (Dr. Bryan, L, 2009)
- Family disputes may increase in frequency as end of life approaches.
- **Reference Lichenthal & Kissane (2008) The Management of Family Conflict in Palliative Care, Feb 1; 16(1):39-45**

Anger towards health care providers

1. Guilt, sorrow and other emotions can be expressed as anger towards care providers.

2. Sources of anger may be shared between the patient and the family. Anger may be directed at those providing care for perceived or actual grievances.

3. Collusion is common

Why deal with family difficulties / stresses?

After all, your job is to look after the patient…

Clinical reasons to address family conflict

1. Unresolved conflict might distract from other aspects of patient care
2. Can have a dire consequence on patient well-being.
3. Not attending to family concerns leads to complaints
4. Responding effectively to those facing bereavement can have a long term impact on how they grieve and their health. (Berry et al, 2017)

Why care for family?

- Family caregiving is typically at the core of what sustains patients at the end of life

- **Reference Pamela, J. K. et al (2006) Family-Centered Care, Journal of Social Work in End-of-Life & Palliative Care, 2:1,13-27**

Family Dynamics

1. Competing preferences for communication and truth-telling
2. Threat of loss can activate dysfunctional patterns of relating, eg over-involvement, detachment, hostility, etc.
3. Uncertainties can provoke tensions (even in the most loving of families)
4. Change of balance in family relationships
5. Past disputes, present rivalries, or even personal demons can get stirred up
6. Stresses may be immediate or long-term

Family Dynamics Contd.

1. Perceived sense of unfair division of labour
2. Mood disorders in patient or family member(s), eg. Depression, anxiety, adjustment disorder, etc.
3. Prevalence estimates vary – one largescale study found 12% advance cancer patients and 13% caregivers met criteria for depressive / anxiety disorder / adjustment disorder(Lichtenthal, Kissane 2008)
4. Longstanding character / personality difficulties can also lead to strain, eg. Borderline Personality Disorder / history of paranoia
5. **Reference Lichenthal & Kissane (2008) The Management of Family Conflict in Palliative Care, Feb 1; 16(1):39-45**

Barriers to Conflict Management

Care providers

1. Lack of time
2. Lack of confidence
3. Fear / dislike of conflict
4. Belief that conflict is best avoided
5. Conflict is not detected

Family Barriers

Barriers to conflict resolution from family perspective

1. Belief that addressing conflict will upset the patient
2. Rejection of offers of assistance due to shame or secrecy, don't want to be the "difficult family".
3. Patient request to not disclose the conflict to 'outsiders'
4. Family may view the conflict as unsolvable / unfixable
5. Previous negative or unsuccessful engagement with health care providers

Top Tips

Top Tips 1

1. Be prepared – understand and accept that family conflict is common in palliative care
2. Don’t wait for the crisis. Take steps at the first signs of tension.
3. Think and plan before reacting!
4. What questions can be asked of patient / family to develop insight into the difficulty / grievance?
5. Look for the underlying cause
6. Avoid avoidance

Top Tips 2

1. Introduce yourself
2. Stay Calm
3. Establish rapport
4. Set Boundaries
5. Outline your rules at the first sign of a problem. Tell people what's acceptable and what won't be tolerated.

Top Tips 3

1. Be alert to early signs of acute psychiatric or personality difficulties
2. Don’t accept abuse
3. Avoid being drawn into family conflict
4. A problem solving approach to conflict resolution results in better outcomes (Beck and Arnold, 2005)
5. What are realistic goals?
6. Keeping focus on your role
7. Timely provision of information that treatment is transitioning to palliative care is helpful for conflict avoidance. These conversations should take place gradually.

Top Tips 4

1. Written Communication, e.g. leaflets can also be helpful
2. If pt. death is expected, discuss in a timely manner appropriate clinical care interventions.
3. Consider a Family meeting / psycho-social education
4. Ensure contact details are up to date
5. Ascertain any religious or cultural practices to be observed
6. Focus on realistic goals

De-escalation

1. Avoid engagement in pressured negotiations with patients and families who are angry and upset
2. Can you move the family member(s) to a quiet room?
3. Acknowledge the anger / verify feelings
4. If anger persists, no matter how justified, invite family to think of consequences
5. Letting families know you're listening, though you may have a different point of view / perspective
6. Reference Back AL, Arnold RM. Dealing with conflict in caring for the seriously ill: 'it was just out of the question'. JAMA. 2005; 293:1374–1381. [PubMed: 15769971]

Who else can help?

- Medical Social Worker
- Chaplaincy
- Liaison Psychiatry
- PALS
- Primary Care Social Work Service
- Vulnerable Adult Social Work Service
- Community Palliative Care
- Voluntary agencies, eg. SAGE
- GP, PHN, CMHT

Self Care

1. Don’t take it personally
2. Know your strengths and limitations
3. Check your internal barometer
4. How can you access support for yourself?
5. Talk to colleagues / debrief
6. Do you have adequate supervision / management support / training?
7. **Reference – Chris Hinz http://dailynurse.com/how-to-deal-with-difficult-family-members-of-patients/**

References

- **Brooks Ashley 10 Terrific Tips for New Nurses Dealing with Difficult Patients**
- **Henkel Gretchen The Challenge of Family The Hospitalist, 2006 (4)**
- **Lichtenthal, W. & Kissane, D. The Management of family conflict in palliative care Progressive Palliative Care, 2008 Feb 1; 16(1): 39-45**