

PSYCHOSOCIAL ASPECTS OF PALLIATIVE CARE IN MENTAL HEALTH SETTINGS

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OUTLINE

- Vulnerability and Compassion
- Addressing the Psychosocial Needs of the Patient
- What do Families Need at EOL
- Staff and Emotional Distress at EOL
- Moral Distress and Moral Residue
- Self-Care

PALLIATIVE CARE

- *“Palliative care is never about informing a patient that nothing more can be done; it’s about what can be done.”*



- (J. Dunphy, 2011, p. 11)

VULNERABILITY

- “Certain dimensions of personhood are particularly vulnerable as death approaches, and this vulnerability is particularly acute for individuals with mental illness.
 - Power differentials- dependency on staff
 - Estrangement from family
 - Lack of continuity of supports
 - Expectation of dysfunction and failure
- (Woods et al. 2008)

WHAT DO PATIENTS NEED AT EOL

- Good medical care that addresses the biopsychosocial/ spiritual needs of the patient
- Relationships with staff that protects the patient's dignity
- Nonabandonment- at times it can be difficult to be present as a patient is dying
- Anticipating Needs
- Finding common ground to develop a care plan despite challenging behaviors
 - What is the person's capacity to understand their illness, death, and dying?
 - Assumptions may be made at times that patients with mental illness are unable to express their preferences related to end of life care.



COMPASSION

COMPASSION

- *“Compassion is the capacity to attend to the experience of others, to come alongside them.”*
- *“It involves attention, being present, showing concern, and being free from bias. Often technology separates, and distracts from the present.”*
 - *Roshi Joan Halifax, Canadian Association of Psychosocial Oncology Conference May 1, (2014)*

COMPASSION

- *“Compassion involves feeling concern for others; our work with dying individuals cannot just be a job.”*
- *“It means feeling sympathy for others, and sensing what will serve others.”*
- *“Moving with deep intention, offering the best outcome for others.”*
 - *Roshi Joan Halifax, CAPO Conference, May 1, (2014)*



FAMILIES AND END OF LIFE CARE



THE EXPERIENCES OF FAMILIES AT THE END OF LIFE

- Anticipatory Grief/Loss
- Depression/Anxiety
- Caregiver Burden/ Guilt
- Fear of the unknown
- Unresolved issues/ multiple losses



ANTICIPATORY GRIEF

- Grief may develop before an individual dies (anticipatory grief), and is often present throughout the person's illness.
- Anticipatory grief may be especially relevant in situations where a patient has dementia.
 - Cognitive decline
 - Loss of personal autonomy
 - Lack of insight and coping with difficult behaviors makes it difficult for caregivers and the individual with dementia to grieve together

■ (Worden, 1991)

ANTICIPATORY GRIEF

- For individuals with end stage dementia this grief can be conceptualized as ambiguous loss:
 - “Being physically present, but psychologically absent”
 - (Boss, 2004)
- Families also experience feelings of grief and loss following the diagnosis of a terminal illness in a loved one, and throughout the disease trajectory

ANTICIPATORY GRIEF AND THE HEALTH CARE TEAM

- Staff can also experience anticipatory grief
 - Long term relationships with patients and families
 - Feeling compassion for the patient given their social/ mental health history
 - In the absence of family/ significant other, staff are the only ones witnessing the progression of illness
 - Staff may find that they identify with a patient's existential suffering and progression of illness, based on their own personal experiences

DEPRESSION AND ANXIETY AMONG CAREGIVERS

- Family caregivers of those who are considered palliative, are prone to negative psychological, physical, social, and financial problems.
- Depression rates 12-59%
- Anxiety rates 30-50%



■ (Hudson , Trauer et al. 2013)

CAREGIVER BURDEN AND GUILT

- Caregiving particularly for individuals with dementia can be all consuming and lead to caregiver burnout.
 - Family members may feel guilty about their inability to do more for their loved one at the end of life.
 - Some family members may experience ambivalence:
 - feeling guilty for wanting their loved ones to die in response to their desire for perceived suffering to be over.
 - Experiencing a sense of relief when their loved one dies may also illicit guilt.
- (Peacock, 2011).

WHAT DO FAMILIES NEED AT EOL

- Communication and information
- Practical support
- Emotional care
- Assistance dealing with dying, death and grief



■ (Muders et al., 2013)

THE NEEDS OF STAFF PROVIDING END OF LIFE CARE



STAFF AND EMOTIONAL DISTRESS IN PALLIATIVE CARE

- Staff often experience stress in relation to:
 - Emotions/behaviors evoked by the dying patient and or family members.
 - Internal distress (discomfort in dealing with death and dying, unsure about the right course of action etc.)
 - Stress arising from the work environment (not enough resources, access to resources, lack of knowledge about how best to meet the needs of the dying patient, lack of support from the health care team).

MORAL DISTRESS

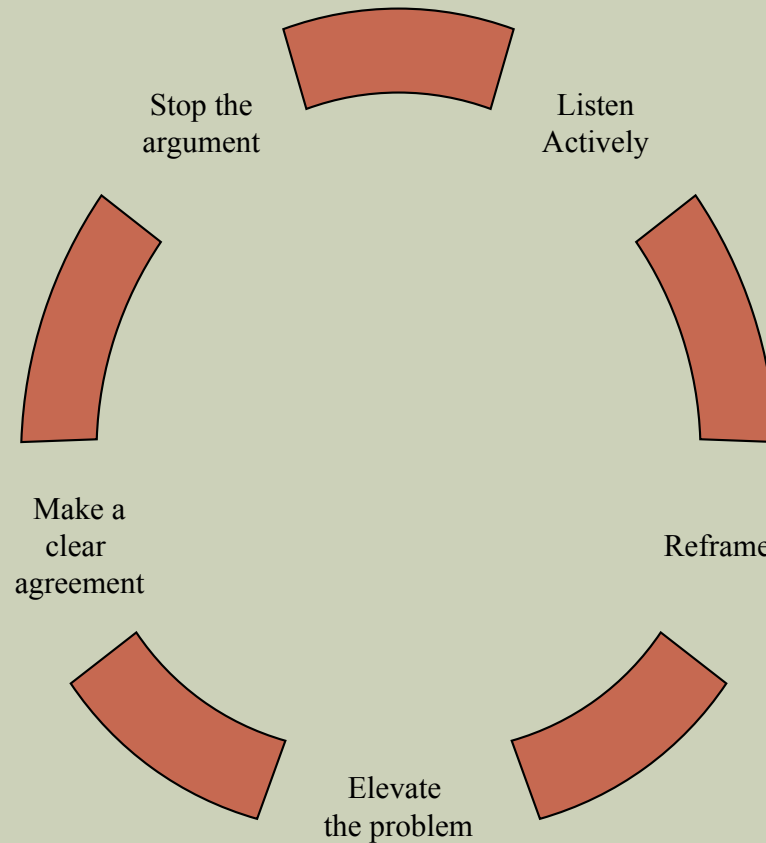
- “The negative feelings that can occur when one knows the right thing to do, but is prevented from doing it through some barrier or constraint.”
- “This leads to the sense that one has compromised their integrity, and can cause significant personal emotional reactions.”
 - (WRHA Patient Care Ethics Decision Making Guide, p. 34, 2015)

MORAL RESIDUE

- “The negative feelings that can arise from involvement in morally distressing situations, that can last for many years, and may manifest via physical, emotional, and professional symptoms, including illness, anxiety, depression, and job turnover.”
 - (WRHA Patient Care Ethics Decision Making Guide, p. 34, 2015)

CONFLICT RESOLUTION STRATEGIES

D. GERARDI (2004)



SELF-CARE FOR STAFF



ADDRESSING THE NEEDS OF STAFF PROVIDING EOL

- What do you do now in terms of supporting each other when a patient is dying?
- How do you support each other, if there is a particularly distressing patient/family situation?

ADDRESSING THE NEEDS OF STAFF PROVIDING EOL CARE

- Talking to each other informally
- Talking with the clinical resource nurse/ manager for support, and other members of the team
- Maintaining healthy boundaries with the patient and family
- Debriefing as a team following the death of a patient
- Creating a ritual to remember the patient

SELF CARE FOR STAFF

- What do you do in order to “leave things at work instead of taking them home?”
- Physical activity
- Relaxation/ deep breathing/ mindfulness
- Engaging in positive self-talk
- Talking to a counsellor/ EAP
- Other ideas?



EMOTIONAL RESILIENCE

- “We do the best we can and humility becomes our companion along the way as we fall down and get back up again and sometimes we learn from our most painful experiences.”
- “We build resilience by accepting our limitations, attending to our own needs, and by practicing “not knowing: trusting in presence”

Halifax (2008)

QUESTIONS/COMMENTS

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