Muddy Waters: When Grief Affects Goals

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Objectives

- Identify various forms of grief encountered in care
- Discuss complications associated with grief
- Identify appropriate interventions to assist in grief management

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Grief in Context

- As a culture we've been taught that grief is a problem to be solved, just put it behind you and move on and you will be ok
  - Our culture doesn't prepare well for death and most people are ill equipped to deal with it
- While we can't "fix" grief, connection and validation go a long way.
  - People may not remember what you say, but they will remember you were there. Companionship is the best thing we can offer.

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Grief in Context

- Not all losses should be seen as opportunities for personal and spiritual growth. Losses can be tragic and so overwhelming that the patient and loved ones are more appropriately focused on emotional, psychological and physical survival as in the case of severe trauma or sudden, violent loss.
- The ideal of a “good death” is helpful to hold as an ideal for many people moving through the natural cycles of life as long as the chaplain carefully assesses and honors the unique needs of each patient and their loved ones and their experience of grief and loss.

Grief in Context

- Anticipatory grief has traditionally been acknowledged as the normal mourning that occurs when death is expected.
  - Results from uncertainty and trying to rationalize the experience.
  - COVID has affected communities broadly and no one is unaffected
- Unsettling feelings can be the result of not knowing what to expect from the disease process or how other factors outside of their control will impact them
  - When these happen before death, it can leave a lasting impression on the griever.
- Complicated grief can present symptoms such as recurrent intrusive thoughts of the person who died, ruminating, excessive bitterness, alienation from previous social relationships, isolation, denial of death, and diminished purpose of life.

Grief and Emotional Distress

- Beginning chaplains learn the art of listening and companioning those who are facing loss and change. Advanced palliative care chaplains learn to assess and engage complex grief with more refined interventions.
- **Grief and Mental Health**
  - In providing support for grief and loss, it is important to recognize when care seekers have an underlying mental health challenge, personality disorder or addiction history. Grief for such care seekers can be exacerbated by existing mental health conditions. These patients may need the support of a psychiatrist as they navigate their experience of grief and bereavement

Disenfranchised Grief	
Example	A young homeless man is admitted to the palliative care service to manage the progression of HIV/AIDS. He is isolated from his family and home community who condemn his gay lifestyle and refuse to visit him in the hospital. The young man is a former evangelical youth leader who left his church community and his family to move in with a gay partner who financially took advantage of him and left him without resources or a home.
Intervention	Validation of grief, loss, and feelings of anger and betrayal; spiritual counseling to allow space for spiritual and religious meaning-making; exploration of forgiveness of self and other in light of betrayal by religious leaders and his community of faith; referral to social work for housing and resources.
Anticipatory Grief	
Example	A woman in her 30s with four children is given the devastating diagnosis of advanced metastatic breast cancer and anticipates a difficult course of treatment that is unlikely to prevent her death. She practices yoga and mindfulness meditation daily.
Intervention	Provide guidance to the patient and her husband about age appropriate spiritual and emotional support for her children; encourage spiritual practices from the Buddhist/Yoga tradition to strengthen positive coping with fear about treatment and anticipated losses; deep listening to offer patient a space to grieve and begin to clarify her goals regarding balancing quality of life and her treatment plan.
Complicated Grief	
Example	A 70-year-old woman is dying of advanced COPD and will soon be admitted to hospice. Six months before her diagnosis, one of her sons was imprisoned for murdering his wife and two children. This patient belongs to a 12-step program. She serves as a sponsor for younger women struggling with alcoholism.
Intervention	Provide emotional and spiritual support for multiple losses; encourage a deeper connection to a higher power; suggest ritual or collage/memorial board to honor each individual loss and its impact; develop quality of life goals that will help maintain patient's connection to her 12-step community once she is home bound.
Ambiguous Grief	
Example	A 55-year-old man is grieving the loss of his wife who is imminently dying after a 20-year struggle with Multiple Sclerosis. He was his wife's primary caregiver for many years. This patient's husband feels guilty about the sense of relief and liberation he feels as he must say goodbye to his beloved life partner. He is an avid hiker and finds a deep sense of peace and greater connection in the natural world.
Intervention	Validate and normalize ambiguous nature of grief; encourage healing connection to the natural world; invite an honoring of all dimensions of this caregiver's experience as equally valuable; encourage self-compassion practice; facilitate a healthy and loving goodbye between the patient and her husband; allow husband time to share his feelings of relief apart from his wife.

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Grief in a Pandemic

- There is no long term information on the psychological processing at end of life during this pandemic, it's easy to see that anxiety and depression are heightened at this time.
  - These likely contribute negatively to the quality of the dying experience, which predicts experiences of complicated grief.
- Individuals may also feel they are experiencing disenfranchised grief, when grief is:
  - Not publicly mourned, isolated experience
  - Bereaved individuals may grapple with the fact that the person they lost was so much more than a statistic and have difficulty fitting their grief within these societal messages.
  - Disenfranchised grief can also occur when families are unable to grieve in traditional practices of funeral services or being unable to attend a loved one's burial.
- Many funeral and burial providers have greatly limited the number of attendees along with other restrictions, creating interesting alternatives to traditional services
  - Funerals play a key role in mourning, bringing together those who remember the deceased to celebrate their life, and creating a supportive network for the bereaved family.
- Though much of the grief outlined previously is focused on that of patients and families, the experiences of providers must also be considered.

Grief in a Pandemic

- During times of crises, many providers rely on strategies of avoidance or compartmentalization to continue treating patients, which can lead to unresolved grief.
  - It's common for caregivers to experience secondary trauma in connection with those in their care. This is both family and staff.
  - Symptoms include excessive worry and fear, feelings unable to "turn off", recurring thoughts, and physical manifestations of stress. Within the additional context of challenging ethical decisions and impacts of new policy decisions.
- Moral distress may be another common experience for providers.
  - The physical or emotional suffering that is experienced when constraints (internal or external) prevent one from following the course of action that one believes is right.
  - Moral distress is a significant issue facing critical caregivers where providers experience emotional exhaustion and depersonalization, or even dehumanization, of the patients and families in their care.
  - This leads to burnout.
- Personal challenges away from work may cause additional grief for providers.
  - Isolating oneself from supports to limit risk of exposure, feelings of guilt for those who are quarantined due to overt exposure or their own diagnosis

We Can Help Others Grieve

Greater attention to the dying patient's emotional well-being helps limit relatives' distress; bereavement outcomes are better when family knows these dimensions of life are being attended to. All frontline staff should be able to provide the basics of culturally sensitive bereavement support, here's some info to help:

- Grief is a normal, natural process
- There's no one way to grieve. One may experience a range of emotions and everyone is different.
- Grief last a long time, a lifetime even.
  - Approximately one in 10 bereaved adults develop prolonged grief disorder, which involves intense symptoms of grief that endure for more than six months after loss, separation distress, intrusive thoughts, and feelings of emptiness or meaninglessness.
- There is no one perfect thing to say
  - We can reduce the grieving person's suffering by focusing on concrete, tangible things like sleep, emotional regulation, and finding new ways to connect with others.

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Suggestions for the Grief Process

- Just hearing someone else's voice can help. Calls don't need to be heavy or emotional, at least not every time.
- End-of-life planning and conversations can relieve anticipatory grief and help create meaning while the patient is still alive.
- Movement. Some people will want to move around more, some may not feel like moving at all. Physical activity is another important dimension of quality of life and taking care of your physical health can assist in the process.

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Addressing Complicated, Disenfranchised, Anticipatory and Ambiguous Grief

- In addition to assessing positive and negative coping, chaplains are trained to engage grief and loss through deep listening, the gift of presence, and simply witnessing the natural unfolding of painful emotions. Yet, the experience of grief is rarely straightforward and simple and many people will experience grief in complex ways. The role of the palliative care chaplain as an advanced spiritual care practitioner is to help the team identify complex grieving and respond with appropriate interventions.
- When considering complex grieving it is important to consider cultural differences that exist in the ways that people grieve. Certain regional and family cultures value emotional expressiveness, for example, while others may grieve in a more reserved and private manner. The goal of assessing coping is to consider values, beliefs, and practices as they are active in the patient's context and not apart from it. There is always a temptation to define those who cope in a way that is similar to our own as coping in a healthy way, while those whose practices may differ are defined as problematic.

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Family Systems Interventions

- Family systems theory provides a helpful way for engaging family dynamics as they unfold for patients with a serious illness. Family systems interventions will often take place in initial or ongoing palliative care consultations with multiple family members and team members present. In engaging the family systems of patients, their loved ones and the interdisciplinary team, competent chaplains can cultivate self-awareness of the chaplain's own role(s) within the system as such roles are activated in patient care encounters and family meetings.
- **Family systems intervention may include:**
  - Bringing attention to family dynamics in a compassionate way to encourage more awareness and flexibility with dynamics as they impact patient well-being.
  - Engaging patients and loved ones in a way that allows for the care seeker's full personhood to be honored in spite of their prescribed role in the family system. For example, approaching a patient who is seen as the "black sheep" or addicted person in the family with a deep appreciation for the aspects of heroism, bravery, and overcoming challenges that make up their life story.
  - Addressing distress that may happen as a result of changes in the family system such as when the matriarch of the family becomes ill and is no longer able to serve as the family organizer and spiritual advisor.
  - Other interventions that take the family as a complex system into account, rather than over-focusing on the individual as the locus of imbalances, problems, and strengths.

Motivational Interviewing and Palliative Care

- While deep listening lies at the heart of the practice of spiritual care, at times it can be helpful for the chaplain to consider a patient's motivation to make positive changes in their lives that will potentially impact the patient's quality of life and the course of their medical treatment. In the U.S. patient autonomy is highly valued and patients have the authority to make decisions that will impact their quality of life either negatively or positively.
- **Motivational interviewing (MI)** is a collaborative, person-centered, goal-oriented method of communication with particular attention given to assessing and strengthening an individual's motivation to take action. MI is a powerful tool that can improve patient engagement, resolve patient ambivalence, and promote patient action in setting and achieving goals.
- Motivational interviewing increases patient autonomy when trained clinicians use the techniques to explore patient values and goals and help patients overcome their reluctance make important changes. Once a patient's goals are clarified, they are then able to put into action the goals they have set for themselves with support from the team.
- Although palliative care is not always associated with helping patients change particular behaviors, there are times when motivational interviewing becomes a helpful method for the palliative care chaplain and other team members.

Motivational Interviewing and Palliative Care

- Motivational interviewing relies on the following principles:
  - **Collaboration vs. Confrontation**: Establishing a partnership grounded in the patient's perspectives
  - **Evocation:** Drawing out "change talk" through engaging the individual's own ideas rather than imposing solutions. Lasting change is most likely to occur when the patient or family discovers their own reasons and motivations to change.
  - **Autonomy vs. Authority**: MI recognizes that the true power for change rests with the pqtient. It is up to the individual to follow through with making change happen.

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Motivational Interviewing and Palliative Care

- The overall goal of motivational interviewing is to respect the care seeker's agency and to assist in exploring and enhancing motivation. The goal is never to change the care seeker's mind. Chaplains are skilled at listening deeply and coming alongside patients in their ambivalence. Motivational interviewing is a direct and more specific way of communicating that can be helpful when patients, loved ones or colleagues face a difficult decision that includes ambivalence about moving forward.
- Motivational interviewing could help a patient or family member clarify whether they will agree to participate in a family conference to discuss their wishes with other family and staff. However they choose to proceed, motivational interviewing techniques along with other spiritual care interventions will have hopefully given them the best chance to fully explore motivations to clarify an empowered path forward.

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Care of Groups and Family Systems

- Palliative care considers the patient and their loved ones to be a decisional unit rather than individual decision-makers. While the patient has certain legal rights to make decisions for themelves, it is best practice to consider how a care plan will impact the family system as a whole. Serious illness affects not only a patient but their family and loved ones who may be grieving as individuals and collectively as a group. It is ideal for a patient and loved ones to make decisions collaboratively so that all the interested members of a patient's intimate circle can participate in supporting the care plan.
- Palliative care chaplains enter the family system of the patients that they serve to care for the individuals and the group as a whole. Palliative care chaplains also provide spiritual care support to their teams and the organizations where they serve.

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The Chaplain's Role in Family Meetings

- Family meetings help define goals of care and convey information to a patient and their loved ones. The chaplain's role in family meetings is essential and often helps to deepen the conversation and open new possibilities for understanding between patients, their loved ones, and the care team
- Chaplains often facilitate family meetings. If the team designates the chaplain as the primary facilitator for the meeting, the palliative care chaplain should be prepared and follow a best practice protocol.

The Chaplain's Role in Family Meetings

- Chaplains often attend the family meeting as a core member of the team without providing the primary facilitation. **As a member of the team, chaplains contribute to family meetings in the following ways:**
  - If at all possible, meet with the patient and family before the time of the meeting to establish rapport.
  - During the meeting, attend to the spiritual and emotional dynamics in the room, including the energy in the space and the affect of the patient, their loved ones, and the other team members. Notice if anyone in the room appears disconnected, withdrawn from the conversation or distressed.
    - If a patient or loved one appears distressed, gently slow down the conversation with statements such as, "I'm noticing that Judy is taking all this in and may need a moment or two to process this new information." Or "I can see that not everyone agrees on this path forward, let's make sure that everyone's perspectives are heard."
    - If a team member appears distressed, follow up with the team member after the meeting to offer to debrief and extend support.
    - Listen to the subtext and emotions beneath what is being said and gently address it. If a family member's body language and words indicate they are distressed or in disagreement with the team, address the response gently. "You said you believe your mother will suffer if we go ahead with this plan. Tell us more about how you believe this plan will make things worse for her.

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The Chaplain's Role in Family Meetings

- Affirm the emotional and spiritual work that the patient and family is doing and let them know they are doing a good job with a difficult conversation.
- If conflict arises in the meeting, normalize the conflict as much as possible. "This is a difficult conversation and it is normal to have differing views. Let's remember that everyone's perspective belongs."
- Draw from the information gained in the spiritual assessment to support the direction of the meeting. If spiritual and religious values are important to the discussion, bring in the important information. It may be necessary to ask for permission first if you are unsure if the patient's information has been broadly shared. "I know that Carla's Catholic faith is important to her. Let's make sure the care plan includes a way for Carla to connect with her faith on a daily basis." Or, "Is it ok if I share the conversation we had about your vacation home, Pete? Pete and I were talking earlier today about how he hopes to spend his last days looking out at that expansive view of the lake."
- While each family has their own spiritual and emotional process, it is important to be aware of the efficiency of time. Family meetings can be long and drawn out if they are not conducted in a deliberate and structured way. When families need more time to process the conversation, the chaplain can attend to emotional responses once the meeting is concluded.
- Encourage the palliative care team to continue to refine the art of conducting successful family meetings. Research and review best practices and encourage a consistent structure. Having a clear plan will go far in allowing for productive and supportive conversations about goals of care

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Connecting Before Death

Family members are often not allowed at the bedside of a dying loved one during a pandemic. This makes connection difficult. There are ways to connect during the pandemic, however.

- Send letters, cards, and meaningful mementos to the dying person's room. Set an environment of love that is patient specific.
- Record a message from the patient to their loved ones that cannot be bedside. There are many apps...too many…to choose from.
- Have friends/family members record their own messages for the patient. These messages can last and be replayed over and over. A patient's hearing is usually one of the last senses to go and familiar sounds can bring great comfort to the dying.
- Zoom isn't just to make you look bad, it's a great way to have isolated patients chat with loved ones if they are able to. Other video conferencing options exist as well.
- Google Home and Alexa are great ways to keep patients and families connected. It's possible to maintain them without the need for staff remaining bedside and can give 24 hour access.
- Don't forget about the kids. They are often more aware of what's going on than we give them credit for. They may have creative ideas to contribute to the experience or need age specific supports.

Mitigating Poor Bereavement Outcomes in Relatives - Before Death

Before a Patient's Death

- Early advance care planning discussions and parallel planning with patients and families
- Timely, proactive, and sensitive information provision and communication with families
  - acknowledge family members' feelings
  - listen to their concerns understand who the patient is
  - Where possible, assign a spokesperson for ease of communication

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Mitigating Poor Bereavement Outcomes in Relatives - Before Death

- Specialist palliative care collaboration, referral, and advice
  - use triage and remote communication where needed
- Optimize symptom management!
- Where possible, allow and facilitate a family member to visit a deteriorating patient
- Facilitate virtual communication using smartphones, tablet computers, and other technology.
  - Be cautious about virtual communication when a patient is actively dying. We also want to ask “what does the patient want?”
- Ensure patients and families have access to emotional, psychological, and spiritual support, including access to chaplaincy

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Advance Directives

- Advance Directives/PT Wishes
  - MPOA
  - Living Will
  - Anatomical Donations
- Recommending to the patient that all decisions made be discussed with family or designees may ensure that those chosen as surrogate decision makers will be willing to represent the patient's designated wishes and values. The advance directive can be amended and changed at any time by the patient as long as she has the capacity to make health care decisions.

POST/POLST

- Physician order for Scope of Treatment
  - complements advance directives
  - an order set rather than a list of descriptions that the advance directive provides
  - state what kind of medical treatment should be provided toward the end of the patient's life
  - signed by a physician and the patient or surrogate decision maker
  - gives patients more control over their lives should they become seriously ill

Ira Byock's Developmental Landmarks and Taskwork for the End of Life

- Though many palliative care patients are not imminently dying, providing care for the dying in the hospital or in a hospice setting is one important dimension of professional palliative care chaplaincy. And for many palliative care patients, coming to terms with a serious illness can lead to the experience of facing one's own mortality, even if the patient is not expected to die in the immediate future. Ira Byock, a physician leader in the field of palliative care medicine, has created a framework for understanding the opportunities for growth that patients and their loved ones face as the patient approaches the end of their life.
- Byock's model is designed to inform caring clinical interventions. Although symptom management is a first priority for the palliative care team, Byock believes it is not the ultimate goal. A more prominent goal for patients and their loved ones is to "preserve opportunities for people who are dying and their families to grow through times of illness, caregiving and grief" (Byock, 1996).

Landmarks	Taskwork
Sense of completion with worldly affairs	Transfer of fiscal, legal and formal social responsibilities
Sense of completion in relationships with community	Closure of multiple social relationships (employment, commerce, organizational, congregational) Components include: expressions of regret, expressions of forgiveness, acceptance of gratitude and appreciation Leave taking; the saying of goodbye
Sense of meaning about ones' individual life	Life review The telling of "one's stories" Transmission of knowledge and wisdom
Experienced love of self	Self-acknowledgment Self-forgiveness
Experienced love of others	Acceptance of worthiness
Sense of completion in relationships with family and friends	Reconciliation, fullness of communication and closure in each of one's important relationships. Component tasks include: expressions of regret, expressions of forgiveness and acceptance, expressions of gratitude and appreciation, acceptance of gratitude and appreciation, expressions of affection Leave-taking; the saying of goodbye
Acceptance of the finality of life - of one's existence as an individual	Acknowledgment of the totality of personal loss represented by one's dying and experience of personal pain of existential loss Expression of the depth of personal tragedy that dying represents Decathexis (emotional withdrawal) from worldly affairs and cathexis (emotional connection) with an enduring construct Acceptance of dependency
Sense of a new self (personhood) beyond personal loss	Developing self-awareness in the present
Sense of meaning about life in general	Achieving a sense of awe Recognition of a transcendent realm Developing/achieving a sense of comfort with chaos
Surrender to the transcendent, to the unknown - "letting go"	In pursuit of this landmark, the doer and "taskwork" are one. Here, little remains of the ego except the volition to surrender.

Case Study #1

- 70 year old female with h/o advanced cholangiocarcinoma complicated by a stroke
  - Poor prognosis due to severity of the stroke
  - Transitioned to comfort care
  - Admitted to inpatient hospice
- She is married and has one son
  - Son has a history of substance abuse
  - Pt husband expressed reservations regarding son's presence at pt's bedside
- Family struggled with course of disease
  - Family were expecting pt to pass away quickly but her clinical course was longer
  - Is there 'something' you can do to speed the process
- Effects on medical management
  - Reservations expressed from family regarding use of opiat

Case Study #2 (cont)

- 40 year old male with h/o tobacco abuse, alcohol abuse, urothelial carcinoma
  - Initial treatment regimen: radical cystoprostatectomy
  - Cisplatin/gemcitabine x4 cycles
  - Initial dx 5/2018
  - Possible metastatic disease noted 5/2019
  - Disease progression noted on PET scan 8/2019
    - Started on pembrolizumab
  - Further disease progression noted on repeat PET scan 10/2019

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- Admitted for uncontrolled pain
- ECOG declined 1—3 in one month
- Unfortunately due to a decline in his functional status he was no longer a candidate for further therapy
- Family meeting held to discuss goals of care
  - Pt expressed anger at ambiguity of his prognosis
  - Loss of time with family
  - Loss of the ability to do his favorite activities
  - Unable to plan for his family
- Effects on goals of care
  - Difficulty with acceptance and transition to hospice

Resources

Web Sites/Emails

- **dying.lovetoknow.com** – this article includes links to online support groups as well as excellent information about both the benefits and risks of online support groups.
- **fullcirclegc.org** – a Richmond-based organization whose website includes a powerful Bereavement Resources Manual (located in the "Resources" section) with lots of helpful information. This organization continues to offer support via telehealth for both individual and group needs.
- **Bereavement Coalition of Central Virginia –** Contact bereavementcoalition@gmail.com
- **refugeingrief.com** – "It's ok to not be ok" is the slogan for this site, which offers resources for those who are grieving as well as tips on how to support someone who is grieving.
- **whatsyourgrief.com** –The site provides blog posts containing practical guidance for those experiencing the death of a loved one.
- **www.good-grief.org -** Good Grief provides free support through peer support programs, education, and advocacy.

Apps

- **Headspace** – headspace.com – this app provides guided meditations to help manage stress, and users can sign up for grief-related support.
- **Ten Percent Happier** – tenpercent.com – this collection of guided meditations, podcasts, and practical teachings can help you work through the intensity of your grief.

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