



Fast Facts Core Curriculum

Psychosocial

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FAST FACTS AND CONCEPTS #19 TAKING A SPIRITUAL HISTORY 3RD

Bruce Ambuel PhD

Background Illness raises fundamental questions – *For what may I hope? Why do I suffer? Does my suffering have meaning? What happens after I die?* When a physician stands with a patient as they face death, the physician inevitably plays a role in supporting the patient's inquiry into these spiritual questions (see *Fast Fact #31 Confronting Personal Mortality*). In addition some patients have specific preferences regarding medical care, death and dying that are based upon their religious beliefs. The physician often plays an important role in supporting a patient's exploration of these issues. Taking a spiritual history is one way to support the patient in this exploration. Maugans (1997) presents a framework for taking a spiritual history; the interview below comes primarily from Maugans' article with some modification based upon the other sources cited. See *Fast Fact #274* for information on the FICA Spirituality History Tool.

Taking a Spiritual History

S—Spiritual belief system

- *Do you have a formal religious affiliation? Can you describe this?*
- *Do you have a spiritual life that is important to you?*
- *What is your clearest sense of the meaning of your life at this time?*

P—Personal spirituality

- *Describe the beliefs and practices of your religion that you personally accept.*
- *Describe those beliefs and practices that you do not accept or follow.*
- *In what ways is your spirituality/religion meaningful for you?*
- *How is your spirituality/religion important to you in daily life?*

I—Integration with a spiritual community

- *Do you belong to any religious or spiritual groups or communities?*
- *How do you participate in this group/community? What is your role?*
- *What importance does this group have for you?*
- *In what ways is this group a source of support for you?*

- *What types of support and help does or could this group provide for you in dealing with health issues?*

R—Ritualized practices and restrictions

- *What specific practices do you carry out as part of your religious and spiritual life (e.g. prayer, meditation, services, etc.)*
- *What lifestyle activities or practices do your religion encourage, discourage or forbid?*
- *What meaning do these practices and restrictions have for you? To what extent have you followed these guidelines?*

I—Implications for medical care

- *Are there specific elements of medical care that your religion discourages or forbids? To what extent have you followed these guidelines?*
- *What aspects of your religion/spirituality would you like to keep in mind as I care for you?*
- *What knowledge or understanding would strengthen our relationship as physician and patient?*
- *Are there barriers to our relationship based upon religious or spiritual issues?*
- *Would you like to discuss religious or spiritual implications of health care?*

T—Terminal events planning

- *Are there particular aspects of medical care that you wish to forgo or have withheld because of your religion/spirituality?*
- *Are there religious or spiritual practices or rituals that you would like to have available in the hospital or at home?*
- *Are there religious or spiritual practices that you wish to plan for at the time of death, or following death?*
- *From what sources do you draw strength in order to cope with this illness?*
- *For what in your life do you still feel gratitude even though ill?*
- *When you are afraid or in pain, how do you find comfort?*
- *As we plan for your medical care near the end of life, in what ways will your religion and spirituality influence your decisions?*

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FAST FACT AND CONCEPT #32
GRIEF AND BEREAVEMENT**James Hallenbeck MD**

Introduction Grief is a normal response to loss, any loss: a job, a limb, a life. Clinicians have an important role in facilitating healthy grieving, and observing for signs of complicated grief. Grief experienced by dying patients and loved-ones prior to and in anticipation of death is called *anticipatory grief (or mourning)*; grief of loved-ones following a death is termed *bereavement*. This *Fast Fact* provides an overview of grief and bereavement.

What is Grief? Grief is a normal response to loss that involves processes and tasks at emotional, cognitive and behavioral levels. The initial shock of learning of impending or actual loss evolves into a process of creating a new relationship between the grieving person and the person (or object) of loss. Grief tends to be experienced in waves, triggered predictably by new losses (such as a loss of functional status) or unpredictably, by seemingly trivial events. Over time the intensity of these waves tends to decrease. Grief does not have a set schedule; individuals progress through the grief process at different speeds. However, no progress, getting stuck in one phase of grief, can be cause for concern.

What is Anticipatory Grief? Anticipatory grief for patients involves reviewing one's life; for families/friends it means looking to a future without the dying person. Byock has suggested that patients and families may wish to say to each other, in some way, "Forgive me, I forgive you, thank you, I love you and good-bye." People from different cultural backgrounds may differ in terms of how and what they want to say or do in preparation for death. Not knowing or acknowledging that a person is dying will likely delay or interfere with normal anticipatory grief. Grief reactions in dying patients may be confused with pain, depression, and even imminent death (e.g. social withdrawal may imply pain, depression, or anticipatory grief).

Distinguishing Grief from Depression Neither pain nor depression are normal aspects of the dying experience, they should be carefully evaluated as both are treatable (See *Fast Fact #43*). Grief tends to be experienced as sadness, whereas depression is associated with lack of self-worth. The question, "*Are you sad or are you feeling depressed?*" may help begin a dialog to help you distinguish between grief and clinical depression.

What is Complicated Grief? About 10-20% of the bereaved can experience a persistent or prolonged period of intense loss. There is debate regarding the precise diagnostic criteria for complicated grief and duration of symptoms (see *Fast Fact # 254* for further information). However, insecure attachment styles, weak parental bonding in childhood, childhood abuse and neglect, female gender, low perceived social support, supportive marital relationships, and low preparation for the loss are all felt to be risk factors.

What can the physician do to facilitate normal grieving?

Be honest when discussing prognosis, goals and treatment options; nothing inhibits normal anticipatory grief more than ambiguity from the physician. Listen; open the door to meaningful discussion. Ask, "How are you doing with this recent news?" "Are you scared?" "Tell me what is going through your mind?" Ask for help – you are not the only health professional available to help with grief. Contact a nurse, social worker, chaplain or psychologist/psychiatrist if you need assistance. Assess for and aggressively treat pain and depression.

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FAST FACTS AND CONCEPTS #43
IS IT GRIEF OR DEPRESSION?**VJ Periyakoil MD**

Background Distinguishing between a dying patient's normal grief and a major depression is a part of routine care for patients near the end-of-life. This *Fast Fact* will review the definitions and clinical features that distinguish these conditions. See *Fast Facts* #7, #32, and #254 for further discussions of depression, grief, and complicated grief.

Definitions

- **Preparatory (or anticipatory) grief.** This is the grief, "that the terminally ill patient has to undergo in order to prepare himself for his final separation from this world" (1). Features include rumination about the past, withdrawal from family/friends, and periods of sadness, crying or anxiety. *Preparatory Grief is a normal, not pathological, life cycle event.*
- **Depression.** Clinically significant depression in a population of dying patients is likely somewhat more common (25-77%) than in the general population (2). However, depression is not an inevitable part of the dying experience and is treatable. Somatic symptoms (anorexia, weight changes, constipation, etc.) are often present as a part of the normal dying process and may not help to distinguish between preparatory grief and depression. Feelings of guilt, hopelessness, worthlessness, and suicidal ideation are the key factors that differentiate grief from depression. When in doubt, treat for depression. Utilize mental health professionals when available. The following additional points are offered to help the clinician distinguish between preparatory grief and depression. Distinguishing preparatory grief from depression

- **Temporal Variation.** A temporal variation of mood is normal in preparatory grief—a mixture of “good and bad days.” In contrast, persistent flat affect or dysphoria is characteristic of depression. Depression is a pathological state; patients can ‘get stuck’ in this state without treatment.
- **Self-Image.** A disturbed self-esteem is not typically seen in grief; however it is a common feature of depression. Overwhelming and persistent feelings of worthlessness to others and of being a burden are common in depression. Distressing guilt is usually generalized to all facets of life in depression, while in grief, the guilt is focused around specific issues (e.g. not being able to attend a child’s wedding).
- **Hope.** A grieving patient’s hope shifts, but is not lost. (Hope may shift from a hope for cure to hope for life prolongation to hope for dying well). In contrast, the depressed patient will comment on feelings of hopelessness and helplessness.
- **Anhedonia.** The ability to feel pleasure is not lost in preparatory grief. Note: grieving patients often need social interaction to help them through the grief process. Anhedonia is an important clue to underlying depression.
- **Response to Support.** Social support helps provide the acceptance and assistance necessary for completion of grief work (3). While social interaction may be helpful in some depressed patients, it will typically not provide the assistance necessary to resolve depression.
- **Active Desire for an Early Death.** An active desire for an early death is not typical of preparatory grief. A persistent, active desire for an early death in a patient, whose symptomatic and social needs have been reasonably met, is suggestive of clinical depression (4).
- **Self-Image.** A disturbed self-esteem is not typically seen in grief; however it is a common feature of depression. Overwhelming and persistent feelings of worthlessness to others and of being a burden are common in depression. Distressing guilt is usually generalized to all facets of life in depression, while in grief, the guilt is focused around specific issues (e.g. not being able to attend a child’s wedding).

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FAST FACTS AND CONCEPTS #47 WHAT DO I TELL THE CHILDREN?

Paula Rauch and Robert Arnold MD

Background The death of a young adult is always difficult, even more so when there are young children survivors. A common question asked by dying adults or their family members is *What do I tell the children?* Physicians and other health care providers can provide leadership and guidance to help young families through this crisis.

I. Screening and awareness

- Ask if the ill person has children at home. Ask about their age, personality, and coping style.
- Ask what the ill person has told the children about the illness.
- Ask if they have a specific worry about the child.
- Ask if the child has had recent problems in school, at home or with relationships.
- Ask who they would like to talk to if they have concerns?

II. Give them some words.

- Often a parent's biggest worry is what to say if the child asks if he or she is dying. Here are two examples of words a parent might use. Asking a parent if these words would feel comfortable to say can begin a dialogue between patient and clinician to arrive at language that is honest, and life affirming.
- **"X" can kill people, but I am taking the best care of myself I can. I am following the doctor's plan so that I can live as long as possible.**
- **Even with trying my hardest and getting the best possible care, my ____ is getting worse; still I plan to live every day.**

III. Give adults concrete examples to guide their interactions.

- Express interest in the child's day.
- Work to maintain normal routines (e.g. maintain family rituals: Friday night supper, Monday night pizza, watching television together).
- Welcome all questions but do not force discussions. Make sure you understand the real question before answering. Take your time to think about how you want to answer.
- Overhearing bad news is the worst way to hear it. Talk with children from diagnosis onward, being sure to give updates when there are changes in prognosis or treatment.
- Avoid euphemisms (e.g. lump, boo-boo, or sickness) that may confuse children.
- Ask children to share what they are thinking, or hear from others, so they do not worry alone.
- Prepare children for visits with the sick person. Describe what they are likely to see. Bring along another adult who is comfortable to stay only as long as the child wants. Bring along markers and paper, so children can leave the parent with a picture or message.
- Talk to the child's teacher or guidance counselor to alert the teachers. Ask teachers and the child's friends' parents to let the parent know if the child talks about worries.

IV. Refer adults to one of the popular books on the subject (Kroen, McCue)

V. Know the resources for parents and children in your hospital and community

VI. Consider referral to a child life specialist or mental health professional when any of the following occur:

- Symptoms of depression or anxiety that interfere with school, home or with peers
- Risk taking behavior
- Significant discord between the child and the surviving parent
- Significant discord between the parents
- The child says he or she wants to talk to someone outside of the family.

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FAST FACTS AND CONCEPTS #56 WHAT TO DO WHEN A PATIENT REFUSES TREATMENT

Robert Arnold MD

Background A core aspect of American bioethics is that a competent adult patient has a right to refuse treatment, even when the physician believes that the treatment would be beneficial. At such a time it is easy to either question the patient's capacity to make the decision or try even harder to convince them to change their mind. The empirical literature – both in decision making and in medicine – suggest that this is a false dichotomy and that there is a third more productive way to proceed. The method described below is applicable to all situations of conflict between clinicians and their patients/families; the astute reader will note the similarity between this approach and that presented in *Fast Fact #26, The Explanatory Model*, designed to assist mediating conflicts that arise in cross-cultural encounters.

Clarify Decisionality Distinguish between patients who cannot understand the medical situation (and thus may lack decision making capacity) and those who understand your viewpoint but do not agree with it. Ask, *I have talked with you about the medical problems you are facing and possible treatments for these problems. Just to make sure we are on the same page, can you describe for me the medical problems you are dealing with now? Can you also describe the possible treatments we have discussed?* (See *Fast Fact #55* for more on decisionality.)

Understand their story Try to understand the patient/family's story before you try to change their mind. This means suspending your attitude toward their decision and as openly and non-judgmentally as possible, understanding the reasons for their decision. This can be done by asking, *Tell me more about your decision – what leads you to this conclusion?*

Validate concerns Often when we try to convince others of our position, we forget to acknowledge the reality of their concerns. This makes them feel unheard and under appreciated. More effective are responses which first let the person know they were heard (*So you are concerned that if you have surgery you will X*) or that normalize their concerns (*It is not that unusual for people to be afraid of XX*) before you respond to these issues.

Explore fears Fears are stronger motivators than positive inducements. Try to understand your patient/family's fears/concerns with your plan of action; you can only address their fears if you understand them. Ask, *Can you tell me if there is something about this decision that frightens you?*

Establish a win-win position If the patient's concern is the lack of control in the hospital and your concern is her/his health if s/he leaves the hospital, what can you do to provide more control in the hospital? Negotiate so both of you can achieve what each of you care about the most.

See the related Fast Facts #16, 17, 24, 26, 29, 59.

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FAST FACTS AND CONCEPTS #59 DEALING WITH THE ANGRY DYING PATIENT

Rebekah Wang-Cheng MD, FACP

Background Anger is a common emotion expressed by seriously ill patients and their families. A typical reaction by the health professional, confronted by the angry patient or family, is to either *get angry back* or to physically and psychologically withdraw; neither are particularly helpful coping strategies. A guide to managing these situations is presented below.

Look for the underlying source of anger. Fear is probably the most common source of anger, especially in the dying and their families – fear of the unknown, being in pain or suffering, the future well-being of family members, abandonment, leaving unfinished business, losing control of bodily functions or cognition, being a burden to the family, and dying alone. Other sources of anger include: 1) a genuine insult – so called “rational anger” (e.g. waiting six hours to see the doctor); 2) organic pathology: frontal lobe mass, dementia or delirium; and 3) personality style/disorder – the person whose approach to much of life is via anger or mistrust.

Recognize the direction of anger. Recognizing the difference between internal and external anger is critical to effective management, because internal anger may lead to potentially harmful patient consequences. When the patient directs anger internally because of fear and guilt (e.g. *I didn't take care of myself; I'm abandoning my family.*), this can lead to withdrawal, self-neglect, anxiety, depression, or a combination of these. Others direct their anger outward at physicians, hospitals, family members or a deity. Particularly in the case of an angry parent of a dying child, he or she may feel helpless and guilty about many things – not bringing the child for medical care soon enough, not being a loving enough or “great” parent (1). This internal guilt and blame can then be displaced towards health care professionals.

Engage rather than withdraw from the patient. The natural tendency for clinicians is to cut short the office or hospital visit, find ways to avoid contact with the angry patient or family member, or to try to mask his/her own anger in order to continue to interact with the patient. Robert Houston MD has written a very helpful article listing 10 rules for engaging the dying patient which will have a beneficial impact on the physician/patient relationship and the quality of the patient's end-of-life experience (2). One of his most important tips is to refrain from personalizing the anger when the patient accuses you of “missing the diagnosis” or under treating the pain. Some of his rules which are pertinent to this discussion are:

- Engage the patient, but do not enmesh with and do the emotional work for the patient.
- Maintain adult-adult communication rather than fostering the patient's dependency.
- Do not personalize the patient's anger.
- Adopt a patient-centered worldview by ascertaining his/her values, priorities, hopes.
- Normalize anger so that the patient can move through this stage.

Use the "BATHE" approach to create an empathic milieu (3). As with any difficult patient situation, communication techniques are especially important so that both the patient and physician do not become further embittered and frustrated.

- **Background:** Use active listening to understand the story, the context, the patient's situation.
- **Affect:** Name the emotion; for instance, *You seem very angry....* It is crucial to validate feelings so the angry person feels that you are listening. Attempting to defuse it, counter it with your own anger or ignore it, will be counter-productive. Acknowledging their right to be angry will help start the healing process and solidify the therapeutic relationship.
- **Troubles:** Explore what scares or troubles the most about their present and future. Just asking the question *Tell me what frightens you?* will help them to focus on circumstances they may not have considered.

- **Handling:** Knowledge and positive action can help mitigate fears and reduce anger. How are they handling the dying – are they making concrete plans about their finances, their things, their family? Have they thought about formal counseling to help deal with the depression, the anger?
- **Empathy:** By displaying empathy and concern you can help the person feel understood, less abandoned and alone. Avoid trite statements such as *I know what you're going through*. Paraphrasing the patient's comments is an effective way to convey that you heard and are seeking to understand: *You feel like it's so unfair that the cancer appeared out of nowhere after all these years*.

Summary The journey from life to death almost always is accompanied by some degree of anger. A caring, patient clinician can assist the patient and the family in recognizing, mobilizing, and modifying the anger into positive emotional energy. Established communication approaches are available such as BATHE which have shown improvements in self-efficacy for communicating with angry patients.

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FAST FACTS AND CONCEPTS #65
ESTABLISHING END-OF-LIFE GOALS: THE LIVING WELL INTERVIEW
Bruce Ambuel PhD

Introduction “When a person faces a fatal disease that is likely incurable, he or she faces specific decisions not only about medical treatment but also about broader, existential issues concerning the best way in which to spend his or her remaining time.” (Hammes 1998)

Clinician-patient discussions about end-of-life treatment are often framed as a choice between “medical treatment vs. treatment withdrawal.” When framed in this manner, treatment withdrawal is a negative choice that often implies giving up, abandonment, not giving the doctor a chance to do his or her job, and not caring; this option would seem to be no option at all.

Bernard Hammes PhD suggests that clinicians reframe the clinician-patient dialogue about end-of-life treatment by starting a conversation with the patient focused on the question “How can we help you live well?” The goal of the *living well interview* is to elicit the patient’s perspective regarding how they want to spend their remaining time. Treatment decisions are then discussed within this broader context of patient goals and hopes. Consequently, medical treatments become tools for achieving patient goals.

The Living Well Discussion

- **When:** Begin soon after the diagnosis of a life-limiting condition.
- **Who:** Clinician (e.g. physician or advanced practice provider), members of the IDT (social worker, chaplain, nurse, psychologist, etc.) the patient, and family and/or other support persons.
- **How:** Begin by expressing a need and interest to understand the patient’s views. The clinician’s initial goal is to develop a broad understanding of the patient’s hopes and goals, not to develop a specific medical plan. Utilize chaplains, social workers, psychologists and other members of the IDT in this discussion, as these professionals can draw upon their well-developed skills in empathy, compassion, and communication to attain a broader perspective of the patient’s views, as well as foster clinician skill development in interviewing within the living-well framework. Specific treatment decisions are then made only after the patient and IDT have developed an understanding of the patient’s broader goals.
- **What to say:** *Given what we now know about your medical condition...*
 - *How can we help you live well? What makes you happy?*
 - **Maintaining or fulfilling what activities or experiences are most important for you to feel your life has quality, or for you to live well?**
 - *What fears or worries do you have about your illness or medical care?*
 - *If you had to choose, would you want us to focus on helping you live longer even if that made you feel worse or on feeling well even if that meant you may not live as long?*
 - *What needs or services would you like to discuss?*
 - *What do you hope for your family?*
 - *Are there any special events or activities that you are looking forward to?*
 - *What sustains you when you face serious challenges in your life?*
 - *Do you have religious or spiritual beliefs that are important to you?*
 - *In what way do you feel you could make this time especially meaningful to you?*
 - *Most medical care is about making small sacrifices in the interest of improving your health for tomorrow. But considering your underlying illnesses, I am hoping you can guide me in helping you make today a better day for you.*

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FAST FACTS AND CONCEPTS #120
PHYSICIANS AND PRAYER REQUESTS**Kate Kwiatkowski, Robert Arnold MD, David Barnard PhD**

Background Physicians are commonly asked to pray for a patient or to lead a patient/family in prayer. The physician may feel conflicted because of uncertainty about how to be supportive to the patient, respect professional/personal boundaries, and remain true to his/her own religious beliefs. The following options attempt to respect the integrity of the physician's spiritual/religious beliefs and be supportive of the patient's emotional needs.

Options:

1. **Pray with/for the patient:** It is entirely appropriate for physicians to pray if they feel comfortable doing so and such prayer is consistent with their own spirituality (see, however, 'Pitfalls' below).
2. **Sit with patient while patient prays:** A physician who is uncomfortable praying with/for the patient may choose instead to sit quietly in supportive company while the patient prays. In this way, physicians lend support to the patient and his/her spiritual beliefs without explicitly endorsing a particular belief system themselves.
3. **Respectfully decline:** Physicians who are uncomfortable with either of the above options may respectfully decline to pray with/for the patient. To avoid the patient feeling rejected, the physician may want to say: *I am really sorry, I am not comfortable with that [eg. leading a prayer].* In such cases, physicians are encouraged to make non-religious supportive comments: *You will be in my thoughts.*

Note: Patients who ask for prayers may have unmet spiritual needs. A chaplain can assist patients talk or reflect upon their spiritual issues. The physician should ask the patient about referral: *Would you like to visit with the hospital chaplain? Or – Would it be helpful for the hospital chaplain come and spend some time with you?*

Pitfalls:

1. It is inappropriate for the physician to impose his/her religious beliefs on the patient or to offer prayer in a manner that is not respectful of the patient's beliefs. Given the differences in beliefs and practices, even within specific denominations, non-denominational prayer is safest. For example, rather than referring to Jesus, Buddha or Allah, use a more neutral and inclusive term like God. Asking God for support or that God's will be done is safer than asking for specific outcomes, particularly if you think the patient is dying.
2. A physician should not promise to pray for a patient if s/he has no intention of doing so. This has the potential to undermine trust in the physician-patient relationship.

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FAST FACTS AND CONCEPTS #156
EVALUATING REQUESTS FOR HASTENED DEATH**Tim Quill MD and Robert Arnold MD**

Background A patient's request to a health care professional to help hasten death is not uncommon. The motivation for this request is usually a combination of relentless physical symptoms, progressive debility, in combination with a loss of sense of self, loss of control, fear of the future, and fear of being a burden on others. Some physicians are frightened by these requests, feeling that they are being asked to cross unacceptable professional boundaries. Others may be tempted to quickly accede, imagining that they would want the same thing in the patient's shoes. But requests for a hastened death may provide awareness into a patient's experience of suffering, and may lead to opportunities for more effective treatment if fully evaluated. In general, the clinician should clarify, explore, evaluate, intensify treatment, and support the patient to ensure a full understanding of the request and to ensure that all alternatives have been considered before responding. This *Fast Fact* provides guidance on how to evaluate and initially respond to a patient who raises the topic of a hastened death. *Fast Fact* #159 will explore how to respond when the request for a hastened death persists after a full evaluation and search for alternatives.

1. **Clarify** which question is being asked before responding. Is the patient simply having thoughts about ending his life (very common), or is he exploring the possibility of a hastened death in the future if his condition deteriorates, or is he exploring your willingness to assist right now (1, 2)?
2. **Support** the patient, and reinforce your commitment to trying to find a mutually acceptable solution for the patient's problem and to continue to work through the process. This does not mean violating fundamental values, but it does mean searching in earnest with the patient and family to find a way to approach the dilemma (3). Attend to your own support by discussing the patient with trusted colleagues and/or with your multidisciplinary team.
3. **Evaluate** the patient's decision-making capacity. Is she seeing her medical condition clearly? Is the request proportionate to the level of unrelieved suffering? Are there dominating aspects of anhedonia, worthlessness and guilt, or is the capacity for pleasure and joy preserved in some small ways? Is this request consistent with the patient's past values? Get help from an experienced psychiatrist or psychologist if you are unsure (4).
4. **Explore** the many potential dimensions that may contribute to the patient's "unbearable" suffering to be sure you (and the patient) fully understand its underlying cause(s). Sometimes it may be an unrelenting physical symptom, other times feelings of depression, or a family or spiritual crisis, or perhaps a combination of many factors (1, 2).
5. **Respond** to the associated emotions, which may be strong and conflicted. Try to empathically imagine what the patient is going through and asking for. Distinguish your own feelings and reactions from those of the patient.
6. **Intensify treatment** of any potentially reversible elements of the patient's suffering. Depending on the patient's circumstances, offer to increase treatment of pain or other physical symptoms, consider biological or interpersonal treatment of depression; see if an appropriate and acceptable spiritual counselor is available. Be creative and brainstorm potential solutions with your multidisciplinary team (1, 2).
7. **Respond** directly to the request for hastened death only after this multidimensional evaluation has been completed. If the patient has full decision-making capacity and all alternative approaches to the patient's unbearable suffering have been fully considered, then re-explore exactly what is being requested, and look for mutually acceptable ways to potentially respond – see *Fast Fact* #159 (5). Note that many patients may be looking for the potential of an escape they will never use, but a smaller number will be looking for a way to hasten death in the present.

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FAST FACTS AND CONCEPTS #159 RESPONDING TO A REQUEST FOR HASTENING DEATH

Timothy Quill MD and Robert M Arnold MD

Background Requests for hastened death among terminally ill patients occur commonly (see *Fast Fact* #156). With good symptom management, psychological and spiritual support, most patient requests do not persist. This *Fast Fact* focuses on ways of responding to patients with persistent wishes for a hastened death despite every effort to find appropriate alternatives. This *Fast Fact* does not address such requests by surrogate decision makers of patients who have lost decision-making capacity.

1. **Reflect on your personal feelings about the request and discuss with other professionals.** These cases are emotionally and ethically difficult. Brainstorm options with other members of the care team including physician colleagues, nurses, psychologists, chaplains and others. Allow trusted colleagues to support your emotional reactions.
2. **Seek out consultation/2nd Opinion.** Make sure you understand the medical, legal and ethical issues involved in responding to a particular request for hastened death. Palliative care and/or ethics consultations are invaluable. Independent second opinions may be helpful in clarifying the prognosis and ensuring that all potentially effective therapeutic alternatives have been considered.
3. **Learn the possibilities.** Possibilities are listed below from least to most ethically controversial. Considering these possibilities assumes that aggressive measures to control physical, psychological and spiritual suffering have been exhausted and/or rejected by the patient:
 - **Withdrawal of life-sustaining treatments.** While most clinicians consider stopping invasive treatments under these circumstances (e.g. ventilators, ICDs, feeding tubes), simpler therapies such as insulin, antibiotics, oxygen, or steroids might also be voluntarily discontinued if they are prolonging life against the patient's wishes. (Unlike the other possibilities, there is widespread legal and ethical consensus about the permissibility of this response based on the right to bodily integrity.)
 - **Voluntary withdrawal of oral intake.** Patients may choose to stop eating and drinking to shorten the dying process. Completely stopping oral food and liquids will typically result in death within two weeks.
 - **Sedation for severe intractable physical symptoms** (see *Fast Facts* #106,107). The intent of sedation is to relieve intolerable suffering by a reduction in patient consciousness. If artificial hydration and feeding are simultaneously stopped, death will come within 1-2 weeks.
 - **Assisted Suicide.** Assisted suicide is defined as someone who provides the means for another person to end their life (e.g. prescribing an overdose amount of medication), but the patient is the one to decide if and when the medicine is actually used, and the patient is responsible for taking the medicine. Physician-assisted suicide is illegal in the United States except for selected states (e.g. Oregon, Washington, Vermont, and Montana).
4. **Decision making process.** Have a detailed conversation regarding the risk and benefits of the different possibilities that fit the patient's clinical circumstances, and which the patient, family and you find ethically acceptable. Be as specific as possible, and document your thinking process clearly. Thus, if stopping eating and drinking is being considered, be sure everyone understands the importance of complete cessation of drinking or else the process can take months rather than weeks.
5. **Balance integrity and non-abandonment.** It is not always possible to find common ground between the patient and physician. When asked if one can support a particular act, a physician needs to be as specific as possible about what he/she can and cannot do, and why. While the physician should not violate personal principles to respond to a request he/she finds unacceptable, he/she should search in earnest with the patient and family for alternative

options that might be mutually acceptable. Typically, this approach will allow the physician to maintain integrity while not abandoning the patient, even if agreement on the particular act in question is not possible (1-4).

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FAST FACTS AND CONCEPTS #172 PROFESSIONAL-PATIENT BOUNDARIES IN PALLIATIVE CARE

Lise Taylor Barbour MD

Background Boundaries in patient care are “mutually understood, unspoken, physical and emotional limits of the relationship between the trusting patient and the caring physician or provider” (Farber 1997). Health professional boundaries represent a set of culturally and professionally derived rules for how health professionals and their patients interact. Boundaries serve to establish and maintain a trusting provider-patient relationship and help clinicians maintain “justice and equity in dealing with all of their patients”, not only a special few (Spence 2005). This *Fast Fact* reviews issues in health professional-patient boundaries in palliative care.

Causes of Boundary Problems In caring for seriously ill or dying patients it is common for strong emotional bonds to develop. However, when the limits of the provider-patient/family relationship are not clear or where normal professional boundaries are not respected, problems are likely to arise. Common reasons for boundary problems include:

- Personality styles or psychiatric disorders in which normal boundaries are not recognized or respected.
- Health professional stress/burnout (see *Fast Facts* #167-170).
- Cultural misunderstandings.

Examples Warning signs and examples of potential boundary blurring include:

- Gift giving from/to patient/family.
- Patients having or wanting access to provider’s home phone number, or other personal information.
- Patient/family expectations that the provider will provide care or socialize outside of clinical care settings.
- Patient/family requests that the provider participate in prayer (See *Fast Facts* #120).
- The health care provider revealing excessive personal information with patient/family.

Self-Monitoring Not all ‘boundary issues’ are detrimental to the provider-patient relationship – some clearly enhance compassionate care and serve to reinforce a trusting therapeutic relationship. However, it is important for the provider to self-reflect when boundaries are approached.

- *Am I treating this patient or family differently than I do my other patients?*
- *What emotions of my own does this patient/family trigger and are the emotions impacting my clinical decision-making?*
- *Are my actions truly therapeutic for the patient, or am I acting in a manner to meet my personal needs?*
- *Would I be comfortable if this gift/action was known to the public or my colleagues?*
- *Could this boundary issue represent a sign that I am experiencing professional burnout?*

Managing boundary concerns

- Set clear expectations with patients and families as to your role in the context of their care, your availability and best ways to communicate with you.
- Use professional colleagues or a mental health professional as a sounding board when you are uncertain about your own or your patient/family behaviors.
- Address issues as they arise with the patient/family. Acknowledge importance of feelings, emphasize the provider-patient relationship and the importance of maintaining objectivity; emphasize that the rejection of a requested behavior does not imply a lack of caring.
- Seek professional counseling for yourself or the patient/family when boundary issues impact your ability to provide objective, compassionate care.

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FAST FACTS AND CONCEPTS #186 ANXIETY IN PALLIATIVE CARE – CAUSES AND DIAGNOSIS

Joseph Stoklosa, Kevin Patterson MD, Drew Rosielle MD, and Robert Arnold MD

Background *Anxiety* is a state of apprehension and fear resulting from the perception of a current or future threat to oneself. The term is used to describe a *symptom* and a variety of *psychiatric disorders* in which anxiety is a salient symptom. This *Fast Fact* will discuss the causes and evaluation of anxiety.

Prevalence Anxiety is commonly reported in those facing life-threatening illnesses. At least 25% of cancer patients and 50% of CHF and COPD patients experience significant anxiety. At least 3% of patients with advanced cancer and 10% of COPD inpatients meet DSM criteria for Generalized Anxiety Disorder (see below).

Etiologies

- Anxiety may be present as part of one of several psychiatric disorders (see below).
- Anxiety is often a prominent component of acute or chronic pain, dyspnea, nausea, or cardiac arrhythmias.
- Adverse drug effects: corticosteroids, psychostimulants, and some antidepressants.
- Drug withdrawal: alcohol, opioids, benzodiazepines, nicotine, clonidine, antidepressants, and corticosteroids.
- Metabolic causes: hyperthyroidism and syndromes of adrenergic or serotonergic excess.
- Existential and psychosocial concerns about dying, disability, loss, legacy, family, finances, and religion/spirituality.

Psychiatric Disorders with anxiety as a prominent symptom

- **Generalized anxiety disorder** is a psychiatric disorder characterized by pervasive and excessive anxiety and worry about a number of events or activities (such as work or school performance), occurring more days than not for at least 6 months. The anxiety and worry are associated with at least 3 of the following 6 symptoms: restlessness, easy fatigue, difficulty concentrating, irritability, muscle tension, and sleep disturbance.
- **Panic disorder** is characterized by recurrent panic attacks. See *Fast Fact* #145 for its evaluation and management.
- **Adjustment disorder** occurs within 3 months of a major stressor, and causes marked distress and functional impairment. Usually it is characterized by a depressed mood but anxiety can also be its most prominent affective component.
- **Acute- or post-traumatic stress disorders** occur after an emotionally traumatic life-event and are characterized by anxiousness and arousal, as well as by numbness, flashbacks, intrusive thoughts, and avoidance of stimuli which remind the patient of the trauma.
- **Phobias** are marked, persistent fears brought about by specific situations or objects.

Evaluation

- Complete a thorough history and physical exam, in particular ask about:
 - Prior episodes or anxiety, depression, PTSD, alcohol, and drug use.
 - Prior and current treatment by a mental health professional.
 - Presence of specific trigger situations or thoughts leading to anxiety.
 - Presence of apprehension, dread, insomnia, and hypervigilance; as well as physical symptoms such as diaphoresis, dyspnea, muscle tension, and tremulousness.
- Seek help from a professional familiar with the psychiatric disorders when anxiety is a prominent and functionally impairing part of a patient's symptoms.
- Symptoms that can be confused with anxiety are agitated delirium (see *Fast Facts* #1,60) and akathisia, an unpleasant sense of motor restlessness from dopamine-blocking medications such as antipsychotics and some antiemetics.
- Formal screening tools exist, but there is no consensus on the benefit of their routine use. Commonly used tools which evaluate for anxiety as a symptom include the Edmonton

Symptom Assessment Scale, the Memorial Symptom Assessment Scale, and the Hospital Anxiety and Depression Scale.

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**FAST FACTS AND CONCEPTS #203
MANAGING ONE'S EMOTIONS AS A CLINICIAN**

Donna Posluszny PhD and Robert Arnold MD

Background It is normal for clinicians to experience an array of emotions when interacting with ill patients and their families. Although positive emotions such as joy and satisfaction are rarely problematic, negative emotions such as anger or sadness may interfere with your ability to communicate empathically or even to provide appropriate medical care. This *Fast Fact* focuses on clinicians' emotional responses to patient care. See *Fast Facts* #59, 167-170, and 172 for more on responding to anger, clinician burnout, and professional boundaries.

Sources of Emotion Some of the emotions we experience are direct reactions to what the patient is saying or doing (e.g. an angry patient may trigger our own anger). Difficult emotions may also arise when patients do not act in ways that we like (e.g. feeling frustrated when a patient is not taking medication as prescribed). We may feel sad, helpless, or even guilty when we cannot prevent a patient from further illness or death. We may also experience emotions triggered by our own past experiences, such as a patient who reminds us of a family member (e.g. grief, longing).

Strategies for managing difficult emotions Dealing with one's emotions is a learned skill. Like all skills it takes time and practice. Be patient and keep practicing – look at each experience as a learning opportunity.

- Prior to an interaction you anticipate will be difficult specifically identify what is causing your emotional response. Was it the patient's health behavior, their behavior towards you, their intense emotions, or your own sadness about their condition? If your emotional response is based on your past, acknowledge this and put it aside during the upcoming interaction.
- Practice the interaction ahead of time. Imagine the most likely ways that the patient will react and how you will respond.
 - Clarify your goals. It is unrealistic to expect that you can prevent or control patients from experiencing difficult emotions, especially anger and grief. Acknowledge this and focus on realistic goals: being empathic, listening, disclosing medical information, talking patients through options, and validating their emotions.
 - Don't go it alone. Bring along a colleague or team member who can help if you have trouble controlling your emotions and can give you feedback on what might work better next time.
- **During the interaction recognize when your emotions are impacting your thinking/communicating:**
 - Increased heart rate; feeling flushed, sweating; shallow, rapid breathing; increased muscle tension; speaking rapidly or loudly; repeating yourself; or realizing you are not listening.
- **If you are experiencing intense negative emotions:**
 - Give yourself and the patient time to allow emotional intensity to subside. Listen, rather than speak; allow silence.
 - Validate the patient's experience by naming their emotions ('You seem frustrated'). If you are not sure, pose it as a question ('Are you feeling frustrated?'). Besides being empathic, simply naming what is happening may attenuate your own emotional response.
 - Naming your own emotions is appropriate as long as it does not divert attention from the patient's needs or put blame on the patient. For example you might say, "I am feeling frustrated that there is not more we can do to help you."
- **If you are feeling overwhelmed,** it is appropriate to say, "Please excuse me for one moment" and then step outside the room; resume your interaction once composed.
 - Most patients appreciate certain displays of clinician emotion (e.g. tears), if they occur at appropriate times and are consonant with the tenor of the interaction.
 - However, losing control of one's emotions, including grief (sobbing), is never appropriate in front of patients and clinicians should excuse themselves prior to doing so.

- *Afterwards*, debrief with a trusted colleague or team member about what happened, how you responded, and how you might do it differently next time. A less emotionally involved person can often see things in the interaction that you cannot. Students and residents might ask faculty to come with them the next time they interact with the patient. Repeated episodes of emotional instability may be a sign of burnout and/or need for mental health counseling.

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FAST FACTS AND CONCEPTS #210 SUICIDE ATTEMPTS IN THE TERMINALLY ILL

Sean Marks MD and Drew A Rosielle MD

Background Chronic or advanced medical illness is a significant risk factor for suicidality (1). This *Fast Fact* discusses evaluating and responding to suicidality in patients with life-limiting diseases. **Note:** this *Fast Fact* does not address cases of 'physician assisted suicide' which have occurred after a deliberative process including psychiatric screening such as in Oregon in the US (2).

Ethics

- **Core Principles:** It is a core obligation of physicians to prevent a patient from initiating suicide and to intervene medically to prevent a patient from dying after a suicide attempt (3). This obligation can include detaining and restraining patients against their will and the use of invasive medical interventions such as mechanical ventilation if needed, although such restrictions to a patient's liberty should be kept to the minimum necessary. Most suicidal patients are considered impaired by depression or other mental illnesses and their actions are not considered autonomous, thus justifying detaining patients and providing medical interventions against their will (4). Such interventions can create further opportunities to treat the patient's psychiatric condition, and only 20% of people who are prevented from committing suicide subsequently complete another attempt.
- **Exceptions at life's end:** The above logic is less compelling in terminally ill patients who have attempted suicide, particularly with short prognoses (e.g. <1 month). In these patients most medical interventions are unlikely to restore health or significantly alter the dying process in a way that would materially benefit the patient. Clinicians may opt to forgo certain interventions (e.g. mechanical ventilation), particularly if family/proxy decision makers consider such interventions inappropriate in their dying loved ones. In these situations clinicians are advised to 1) verify the certainty of the very short prognosis, utilizing consultants liberally, 2) discuss with proxy decision makers all possible treatment plans including, when feasible, less-invasive supportive care options with treatment limitations (e.g. ICU monitoring, gastric lavage and charcoal administration for an overdose, but establishing a do-not-resuscitate/do-not-intubate order even if the patient deteriorates), and 3) seek ethics consultation.
- **Advance Directives:** Advance directives such as living wills stating a patient's wish to not be mechanically ventilated are not binding in the setting of a suicide attempt. However, they should be honored in patients with short prognoses per the discussion above. Advanced directives specifying treatment limitations should be re-evaluated if it is suspected those statements were made during a period of undetected depression (5,6).

Epidemiology and Risk Factors There has been limited research into specifically 'terminally ill' populations, hence the rate of suicide in the terminally ill is unknown. What is clear is that advancing age and psychiatric comorbidity are risk factors for suicide along with male sex, AIDS diagnosis, a family history of suicide, and uncontrolled pain (7,8). Cancer patients have nearly twice the incidence of suicide than the general population (rate of 31.4 vs. 16.7/100,000 patient-years) and the first year after diagnosis carries a higher risk (6,9). Lung, prostate, pancreatic, and head and neck cancers have the highest suicide rates among all cancer types (9). Up to 8.5% of terminally ill cancer patients express a sustained and pervasive wish for an early death, and in one survey 10% of terminally ill patients reported "seriously pursuing" physician assisted suicide (10,11). Rates of actual suicide attempts are presumably lower.

Assessment All patients with life-limiting illnesses should be routinely assessed for depression and mood disorders (see *Fast Facts* #7, 43); depressed patients should be screened for suicidal thoughts. Patients who admit to suicidal thoughts or a desire for hastened death should be asked about specific plans for self-harm, past history of suicide attempts, access to firearms or other lethal means to carry out a suicidal act, and level of support/supervision available in the home (e.g. family caregivers). Although some clinicians may be concerned that exploring suicidal

thoughts may make suicide more likely, there is no evidence that this occurs. Many ill patients who express a desire for death are simply communicating unresolved emotional and existential concerns about dying: see *Fast Facts* #156 & 159.

Responding to Suicidal Intent All patients who are seriously threatening self-harm, or who have pervasive thoughts of ending their life, should be evaluated urgently by a psychiatrist (12). Immediate resources depend on local availability and can include prompt evaluation by an established psychiatrist, medical or psychiatric urgent care clinics or emergency departments, or even voluntary hospital admission. Options include voluntary psychiatric treatment, arranging 24 hour safety monitoring from the patient's family and friends, introducing home hospice or home nursing support, removing means to carry out a suicidal act, and imposing emergency detention. For disabled patients close to death, removing the means of self-harm (e.g. limit access to pain medications as long as a reliable family member can administer them) and providing close supervision through, for instance, hospice services are often sufficient and minimally restrictive.

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FAST FACTS AND CONCEPTS #216
ASKING ABOUT CULTURAL BELIEFS IN PALLIATIVE CARE

Hillary Lum MD, PhD and Robert Arnold MD

Background Patients' cultural backgrounds profoundly influence their preferences and needs regarding discussing bad news, decision-making, and the dying experience. This *Fast Fact* offers a framework for taking a 'cultural history' to better understand a patient's and family's needs. See also these related *Fast Facts*: #17 (illness experience), #19 (spiritual history), #26 (explanatory model), #183/184 (conflict resolution).

C – Communication. Identify the patient's preferences regarding how and to whom medical information is shared. *Some people want to know everything about their medical condition, and others do not. How much would you like to know?* For those who request that the physician discuss their condition with family members: *Would you like me to speak with them alone, or would you like to be present?* Identify main contacts to give information to about the patient's condition. Carefully explore with families requests to hide information from a patient (see references #4 and #5; *Fast Fact* #219).

U – Unique cultural values. Use respectful, curious, and open-ended questions about a patient's cultural heritage to identify their values. *Is there anything that would be helpful for me to know about how you and your family view serious illness? Are there cultural beliefs, practices, or preferences that affect you during times of significant illness?* If the patient is open to discussing death: *What concerns do you have about dying? Are there things that are important to you or your family that I should know about?*

L – Locus of decision-making. For some patients medical decision-making is communally driven rather than individualistic. Multiple family members or a community elder or leader may need to be involved, often without prior official documentation because it is assumed or understood from the patient's perspective. *Do you prefer to make medical decisions about tests and treatments yourself, or would you prefer that others in your family or community make them for you?*

T – Translators. Language barriers are extremely challenging, especially during times of severe illness. Utilize medical interpreters frequently and effectively. Refer to *Fast Fact* #154 for a detailed discussion on using interpreters in palliative care.

U – Understanding the patient and learning as a provider. Reassess what is being heard, understood, and agreed upon frequently, from both the patient's and clinician's standpoint. Specifically confirm the patient's understanding or agreement (beyond nodding or "yes" responses). This is particularly important if a medical translator is involved as miscommunication is common even when using trained medical interpreters – see reference (6). *Can you tell me – in your own words – what you have heard from me and what's most important to you about what I've said?*

R – Ritualized practices and restrictions. Determine if there are specific customs the patient desires to be followed. These must be communicated to other health care providers, especially in the hospital setting. It may be necessary to advocate for the patient and negotiate with healthcare facility administrators to find an agreeable way to honor a patient's wishes. *Are there specific practices that you would like to have in the hospital or at home? Are there aspects of medical care that you wish to forgo or have withheld because of your cultural beliefs? Is anything discouraged or forbidden?* If the patient is approaching death, and willing to discuss it: *Are there specific practices that are important to you at the time of death or afterwards that we should know about?*

E – Environment at home. Given that a majority of hospice care happens in the patient's home environment, respectfully explore whether there are any needs that can be met by the health care system, and how open the patient, family or community is to receiving care at home. Recognize that patients may be hesitant to voice needs, or resistant to accepting help from outside the

community. Even if a trusting, collaborative relationship has developed between a patient/family and clinicians in the hospital, this may not immediately translate into the home setting. With the patient's permission, expectations about cultural-specific aspects of a patient's care should be explicitly communicated to care providers outside the hospital.

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FAST FACTS AND CONCEPTS #219
RESPONDING TO REQUESTS FOR NON-DISCLOSURE OF MEDICAL INFORMATION

Elizabeth Chaitin DHCE and Drew A Rosielle MD

Background What do you do when a family member asks you not to tell your patient important medical information such as a diagnosis or prognosis? Requests for non-disclosure can represent a loving family's efforts to protect a patient from emotional harm, an inaccurate assessment by the family about a patient's preferences or emotional resilience, or an accurate reflection of how the patient would prefer to make decisions. This *Fast Fact* will introduce readers to a practical approach to these clinical dilemmas.

The Problem Contemporary medical ethics and professional standards dictate that patients have the right to choose the medical care that best allows them to meet their life goals. To make such choices requires they be fully informed of their condition, prognosis, and reasonable treatment options (see *Fast Facts* #164, 165). One needs to differentiate the right to such information from the duty to hear the information, however. Patients have different preferences for medical decision-making, ranging from individualistic, to paternalistic (doing whatever the physician recommends), to communal (sharing, or deferring, important medical decisions to family members or religious/community leaders). Truly respecting patient autonomy requires clinicians to identify and respect patient wishes to share or defer decision-making, including a patient's preference to not be informed of key medical information.

Prevention Negotiate with the patient *before* the results of testing arrive as to how much information they would like and who they would like to have present for information sharing. *Are you the kind of person who wants to know the results of the test or would you rather I talk to your children?*

Managing Requests for Non-Disclosure (adapted from Hallenbeck and Arnold, 2007):

- *Stay Calm.* These situations can be confusing and emotional for clinicians. The calmer you remain the more information you will gain from the family as to why they do not want their loved one to be informed of the bad news. Demonstrating frustration or implying that the request is inappropriate can break trust and derail your efforts to resolve the situation.
- *Try to understand the family's viewpoint.* They know the patient best and can provide insight into the cause of the request. Politely ask questions to understand the nature of the request. *Can you tell me more about why you feel this way? How does your family typically handle difficult information? How are important decisions made by your family?* Ask about how the patient has responded in the past to bad news and if they have made specific statements to others about what they want to know. Is the family more worried more about *how* the information is given rather than the information itself (e.g. given to the patient when alone, use of 'death' or 'dying,' the disclosure of specific prognostic time-frames)?
- *Clarify what the patient already knows.* Politely ask questions to understand what the family believes the patient already knows. Does the family think the patient already knows or strongly suspects what is going on and would rather not talk further about it, or is the patient completely in the dark? Have other clinicians already told or implied to the patient what is going on? How did the patient respond to that? Is the patient talking with the family about their concerns? A patient's reluctance to talk with family members may represent an attempt to protect them.
- *Respond empathically.* A family's request to not tell their loved ones usually comes from a kind and loving place; they are often frightened for themselves and the patient. Responding empathically (see *Fast Fact* #29) allows them to recognize that you care about them. It may allow them to see your ability to give information to their loved one in a compassionate way.

- *State your views openly, but as your own views.* Disclose any discomfort you have with the family's request; explain your professional obligation to ensure the patient is able to make informed decisions in the manner they prefer. Disclose this specifically in the context of you wanting what is best for the patient, including respecting how she or he would like to hear information.
- *Be willing to brainstorm possible solutions.* Rigidly informing the family that you must tell the patient breaks trust and is inaccurate. There is no 'one-size-fits-all' solution to these scenarios. Often, there are solutions neither of you have thought about that will meet everyone's goals. In other cases, the family may not have thought about the implications of the request (e.g. giving Mom chemotherapy but not telling her she has cancer).
- *Negotiate a solution.* Recommend to the family that you, in their presence, share with the patient a limited amount of information, and then specifically ask the patient if they would like to hear more. Tell the family what you plan on saying, i.e. – *You came to the hospital because you were not eating well and became dehydrated. We have been trying to figure out what is going on. Some people want to know everything about their medical condition, others prefer the doctors talk with family members about what is happening and the best way to help a patient. What would you prefer?* Contract with the family that they, and you, will respect the patient's decision.

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FAST FACTS AND CONCEPTS #252 BORDERLINE PERSONALITY DISORDER IN PALLIATIVE CARE

Laura McLafferty MD and Julie W Childers MD

Background Borderline personality disorder (BPD) is identified by a pervasive pattern of instability of relationships, self-image, and mood, as well as marked impulsivity (1). The prevalence of BPD in the general population is 1-2%, and, despite the impression of a female predominance, evidence indicates that it occurs equally frequently in men and women (2). The stresses of serious illness may bring out these patients' most dysfunctional coping strategies, which can be uniquely challenging for medical professionals. This *Fast Fact* provides strategies for successful interactions with patients and patients' caregivers with BPD.

Diagnosing BPD:

The diagnosis of BPD requires a skilled clinical interview conducted by a knowledgeable examiner who has a longitudinal view of the affected patient. In the palliative care setting, certain behaviors and interactions with other individuals are clues to a BPD diagnosis if not previously established.

- Individuals with BPD evoke strong emotional feelings in clinicians, including both negative emotions (anger, disgust, frustration, and anxiety) and over-identification, which may lead to attempts to "rescue" the patient.
- Individuals with BPD have difficulty sustaining ambivalent feelings and may instead label clinicians as either "wonderful" or "terrible", a defense mechanism known as "splitting".
- Individuals with BPD will go to great lengths to avoid real or imagined abandonment. They may demand multiple provider visits per day and become angry or withdrawn when demands for extra attention or special exceptions are not met. They are more likely to threaten legal action against providers when they perceive that their needs have not been met.
- Impulsive behavior, including inappropriate use of prescribed medications, signing out against medical advice, and inconsistency in decision-making, occur commonly.
- Defects in cognitive functioning, especially decision making, conflict resolution, and "effortful control" (the ability to inhibit or activate behavior to adapt to a situation) affect the ability to make reasoned decisions about medical care and sustain meaningful interactions with loved ones and medical staff.

Strategies for working individuals with BPD (4, 5, 6, 9):

- Remember that the individual with BPD is suffering. Monitor your own feelings and refrain from responding emotionally or aggressively to verbal attacks and manipulation (See *Fast Facts* #59, 172 and 203).
- Begin encounters with a tactful assessment and acknowledgment of the individual's distress, and focus on specific problems. Address problem behaviors directly with statements such as "We want to continue to treat you, but if you threaten to hurt other people we will have to have you escorted out of the clinic".
- Recognize splitting behavior (when clinicians find themselves exuberantly praised or labeled as the 'only one who has ever been helpful' to the patient). Clinicians should avoid excessive familiarity and should instead identify themselves as part of a unified treatment team with a common plan.
- Set explicit limits on disruptive behavior such as angry outbursts or harm to self or property. A written treatment contract which specifies consequences may be helpful. Expect the individual to test the limits and be prepared to respond consistently.

Clinician Self Care and Use of the Interdisciplinary Team

- Frequent debriefing with the interdisciplinary team and key clinicians (e.g., other consultants) where you have an opportunity to share the feelings you experience in working with a BPD patients is essential for practitioner self-care (See *Fast Facts* #167-170).
- Involve the treatment team in setting limits on behaviors (e.g., angry outbursts), visit frequency, and inappropriate use of medications. Carefully document all interactions with the patient or family member, including specific behaviors.
- Utilize consultants. A psychiatric consult-liaison service or the patient's own psychiatrist or psychologist, if the patient has one, should be involved in developing a plan for successful interaction the individual. If a patient's prognosis is long enough, consider

requiring participation in psychological or psychiatric care as a condition of your continued involvement.

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FAST FACTS AND CONCEPTS #254 COMPLICATED GRIEF

René Claxton MD and Charles F Reynolds III, MD

Background The majority of individuals experience normal grief after the death of a loved one (see *Fast Fact* #32). However, about 10-20% of bereaved individuals experience a persistent, debilitating phenomenon referred to as *complicated grief* (CG) (1). Complicated grief has also been referred to as *prolonged* or *pathologic grief* (2); and in the most recent revision of the Diagnostic and Statistical Manual of Mental Disorders (DSM V), CG was relabeled as Persistent Complex Bereavement Disorder (3).

Risk Factors CG is principally considered an attachment disorder (1). Insecure attachment styles (excessive dependency, compulsive care-giving, defensive separation) are correlated with CG. Additionally, supportive marital relationships (characterized as security-enhancing, confiding and emotionally supportive) are correlated with CG after the loss of a spouse suggesting that the loss of a spouse who provides emotional stability and security may lead to an exacerbated grief reaction (4). Other risk factors include weak parental bonding in childhood, childhood abuse and neglect, female gender, low perceived social support, and low preparation for the loss (1,5).

Impact on Health CG is associated with mental and physical health problems including depression, hypertension, work and social impairment and reduced quality of life. Additionally, CG increases an individual's risk of suicide and suicidal behavior (7).

Diagnosis CG shares characteristics with major depressive disorder (suicidal ideation, preoccupation with worthlessness) and post-traumatic stress disorder (re-experiencing intrusive thoughts of the deceased, avoidance of reminders of the deceased and emotional numbness). However these are separate entities differentiated by precipitating events, risk factors, course of illness and response to intervention (2). The precise diagnostic criteria for CG are currently being debated (5). Commonly agreed upon characteristics include:

- yearning, pining, or longing for the deceased
- trouble accepting the death
- feeling uneasy about moving on with one's life
- inability to trust others since the death
- excessive bitterness or anger about the death
- persistent feeling of being shocked, stunned, or emotionally numb since the death
- frequent intense feelings of loneliness
- feeling that life is empty or meaningless without the deceased (refraining from doing things/going places that remind one of the loss)
- frequent preoccupying thoughts about the person that died

Symptoms must cause marked dysfunction in social, occupational or other important domains. The duration of symptoms required to meet criteria for CG has not been defined and varies between six to twelve months after the death (1, 5).

Screening The following *Brief Grief Questionnaire* is a 5-item screening tool scored on a 0-2 Likert scale ('not at all,' 'somewhat,' 'a lot') which has been used to screen for CG (6).

1. How much of the time are you having trouble accepting the death of a loved one?
2. How much does your grief interfere with your life?
3. How much are you having images or thoughts of your loved one when he or she died or other thoughts about the death that really bother you?
4. Are there things that you used to do when your loved one was alive that you don't feel comfortable doing more, that you avoid? How much are you avoiding these things?
5. How much are you feeling cut off or distant from other people since your loved one died, even people you used to be close to, like family or friends?

Expert recommendation is that individuals with scores of ≥ 5 should undergo a diagnostic evaluation by a mental health professional (7).

Treatment A recent meta-analysis on the treatment of CG showed efficacy of interventions including cognitive-behavioral and group therapy in alleviating symptoms with a duration of benefit from 3-6 months. Limitations of the meta-analysis include under-representation of men (average 71% female), small number of studies included (n=5), and small number of participants (n=485, 109 lost to follow up) (8). There have been no randomized controlled trials evaluating the pharmacologic treatment of CG and there is currently no defined role for drug therapy. A randomized trial is currently underway to evaluate the effect of a selective serotonin reuptake inhibitor on CG. Many hospice agencies provide bereavement services, even if the bereaved's loved one was not a patient of the hospice agency.

Bottom Line Most bereaved individuals experience normal grief. A minority will experience long-term, persistent, disruptive symptoms that impair functioning and increase the risk for negative mental and physical health states. Individuals suffering from CG benefit from referral to a trained mental health provider who can administer therapy specific to CG.

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**FAST FACTS AND CONCEPTS #319
EXISTENTIAL SUFFERING PART 1: DEFINITION AND DIAGNOSIS**

Tony Grech MD and Adam Marks MD MPH

Background Patients with serious illnesses often wrestle with existential questions such as: *Why is this happening to me? What is the meaning of my suffering? Where is God?* Typically, these questions do not indicate psychological pathology. However, for some patients (likely 13-18% with progressive illness), these questions can evolve into clinically significant existential suffering that can erode self-worth, correlate with suicidal ideation, and exacerbate physical symptoms such as pain or nausea (1-3). Palliative care clinicians are often faced with the challenging task of identifying when existential concerns are contributing to suffering in a way that a health care team should intervene. This *Fast Fact* will review the definition of existential suffering and common identification tools. *Fast Fact # 320* will review suggested care approaches for a patient with existential distress.

Definition There is no widely agreed upon definition of existential suffering, nor an agreed upon term to describe it. Other terms seen in the published medical literature include “existential distress”, “demoralization syndrome”, and “total pain” (4). One commonly referred to definition is an incapacitating state of despair resulting from an inner realization that life is futile and without meaning (1). Four existential domains have been recognized through which existential suffering can manifest (3,5):

Existential Domain	Description	Clinical Manifestation
<u>Mortality</u>	Awareness of the inevitability of death and a wish for life to continue	Anxiety about dying or the afterlife; concern about separating from loved ones
<u>Freedom</u>	Reality that humans must always choose and all choices have consequences.	Regret about past choices; unresolved conflict with one’s self or others
<u>Meaningless</u>	Struggle to find meaning in life despite the universal reality of death.	Loss of purpose; questioning the meaning of their illness, suffering, or faith
<u>Isolation</u>	Sense of isolation from part of a larger community (church, family, etc)	Feelings of abandonment by community or God; a sense of disconnectedness.

Existential and Spiritual Suffering Existential suffering and spiritual suffering are not synonymous although these phenomena often overlap. Spiritual suffering, defined simply as distress due to spiritual or religious concerns, can be conceptualized as a sub-type of existential suffering. When considering the differences between existential and spiritual suffering, several key points warrant emphasis:

- Some patients with existential suffering may not consider themselves to be spiritual and may become upset if a clinician reflexively consults a chaplain.
- Spirituality has vastly different meanings for different individuals. See *Fast Facts #19* and *274*. In its broadest definition, spirituality can include involvement in a secular club or organization (6).

- Spirituality is part of each existential domain; however, it does not encompass all facets of each existential domain. Therefore, all spiritual suffering is existential suffering, but not all existential suffering is spiritual suffering.
- “Spiritual” and “existential suffering” are not terms patients/families are typically familiar or comfortable with. At the bedside it is best to name the distress explicitly or reflect the patient’s language characterizing the suffering. For example: “*It sounds like you are trying to make sense of how this could happen.*” Or “*you said you’ve felt very apart from your family and faith community since this began. Can you tell me more about that?*”

Clinical Assessment Tools Clinicians should listen for existential ‘cues’ in all patients with serious illness, especially when symptoms seem out of proportion to their disease. Such cues can be expressions of doubt about life’s meaning or one’s faith or expressed feelings of isolation – e.g. “*no one understands what I’m going through.*” Although there are multiple validated assessment tools available to aid healthcare providers in the diagnosis of existential suffering, many of these tools focus on one specific existential domain and others may be too cumbersome to implement into clinical practice. Instead one particularly useful tool involves simply asking the patient: “*Are you at peace?*” (8). A no answer should prompt further exploration of signs of distress, physical or otherwise, with follow-up questions such as “*What’s keeping you from being at peace?*” or “*What worries you the most about your illness?*”.

Risk Factors No associations were found with existential suffering and time since diagnosis, stage of disease, or type of treatment (1). One systematic review identified the following risk factors (7):

- Poor social support: single patients (including divorced, separated, and widowed) or unemployed.
- Poorly controlled physical or psychological symptoms.
- Self-blame coping factors for illness and low sense of controllability of the illness.
- Low level of physical activity.

Diagnostic Challenges A lack of a universally accepted definition, clinician knowledge deficit, and concomitant psychological, spiritual, or social concerns make existential suffering difficult to diagnose. Furthermore, patients may have difficulty articulating their distress or may not be willing to disclose it if they feel their clinicians are too busy or guarded from discussing existential concerns (4). Not all patients with existential suffering develop clinical anxiety or depression. In general, clinical depression can be defined by a loss of interest or pleasure in the present moment, whereas existential suffering is typically defined by a loss of hope, meaning, and anticipatory pleasure (9,10). Despite these challenges, it is important for clinicians who care for seriously ill patients to elicit existential concerns, as doing so can open opportunities for empathetic connection and clarify treatment options. Collaborating with social workers, chaplains, or psychologists is vital to better understand a patient’s suffering.

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**FAST FACTS AND CONCEPTS #320
EXISTENTIAL SUFFERING PART 2: CLINICAL RESPONSE AND MANAGEMENT**

Tony Grech MD and Adam Marks MD MPH

Fast Fact #319 explored the definition and risk factors of existential suffering. This *Fast Fact* will offer clinical guidance on how to respond to patients exhibiting signs of existential suffering.

Reflective Listening While existential questions at the end of life are a natural and common occurrence, for some patients these existential concerns can be associated with overt suffering stemming from a loss of meaning or value in life. When palliative care clinicians encounter a patient with existential distress, they may feel a clinical need to “fix” the existential distress or manage it with clinical therapies. Instead, words communicating empathy and validation of the existential distress may be more comforting. *“I can only imagine how scary this must feel for you. I sometimes wonder how anyone can make sense of this”* is an example of reflective listening phrase which may normalize the patient’s existential distress.

Management Pitfalls Clinicians of seriously ill patients should avoid focusing their clinical assessment solely on physical symptoms. Since existential suffering, spiritual suffering, physical symptoms and psychiatric symptoms may all exacerbate the other, it is important to ensure patients are receiving excellent management of their physical, spiritual, and psychiatric domains. Failure to do so can result in inappropriate dose escalations of analgesics, anxiolytics, or antidepressants. Palliative sedation has been used for refractory existential suffering; however, its use is controversial and in many cases avoidable with the proper engagement of an interdisciplinary team that includes social workers, chaplains, psychologists, and grief counselors.

Psychotherapeutic Modalities A variety of psychotherapeutic modalities may alleviate the multifaceted aspects of existential suffering (1-5). Many of these interventions such as dignity therapy do not require a referral to a trained psychotherapist, as members of the interdisciplinary team (traditionally social workers, nurses and chaplains) can be trained with relative ease (6).

Meaning Centered Group Psychotherapy (MCGP) and Individual Meaning Centered Psychotherapy (IMCP): Founded on Viktor Frankl’s teaching regarding the human need for meaning, MCGP/IMCP is a form of group or individual psychotherapy initially designed for patients with advanced cancer. MCGP/IMCP strives to help patients find meaning in their experiences with illness while exploring philosophical questions of life. The goal is to have patients refocus on living rather than dying, and has been shown to have psychological benefit in patients with advanced cancer (1,2).

Dignity Therapy: This is a brief form of individual psychotherapy which involves a guided interview to allow patients to reflect on past experiences that mattered most to them and how they want to be remembered (legacy). Sessions are often audio-recorded, transcribed, and then provided to the patient to share or pass on to individuals of their choosing (3,4). A recent systematic review demonstrated benefits for both patients and families that sustained after the patient’s death (5).

Supportive Expressive Group Therapy (SEGT): This form of group therapy has its foundation in the benefits of social support and the use of coping skills to help decrease the trauma of a terminal illness often via normalization (initially established for metastatic breast cancer patients). The aim is to create a supportive environment for patients where they can adjust to the demands of their illness while learning to live life fully and authentically and improve their quality of life (4,6). Sustained responses have been demonstrated particular in patients with breast cancer (7).

Communication Pearls For those patients who are too ill to participate in formal psychotherapy, a thoughtful, empathetic presence may relieve, to a degree, the existential suffering many patients experience. Examples of common clinical questions which utilize the

tenets of psychotherapeutic modalities to help patients explore their existential distress and seek meaning in their illness include:

- *It sounds like you have a lot on your mind. What in particular is causing you the most concern?*
- *Tell me a little about your life, particularly those parts you remember most or think are most important.*
- *What are the most important roles you have played in life (family roles, vocational roles, community-service roles, etc)? Why were they so important to you? What did you accomplish in those roles?*
- *Are there particular things that you feel you still need to be say to your loved ones or say once again?*
- *How do you want to be remembered by your loved ones?*

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