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Challenging interactions with patients and families in palliative care

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INTRODUCTION

Palliative care specialists are frequently asked to care for patients at a time of vulnerability or crisis. When difficult interactions with patients and/or their family members occur, optimal care delivery can be compromised. All clinicians have patients they find particularly challenging. Most commonly, providers identify patients and families as “difficult” when the clinician is frustrated in the relationship or with how the patient seeks health care [1].

This topic review will provide a practical and safety-oriented approach to challenging interactions in palliative care settings, which manifest most commonly as behavioral problems or communication difficulties between patients or their family members and clinicians.

Issues related to the care of adults who are deemed incompetent, intimate partner violence, and child or elder abuse are discussed elsewhere. (See "[Legal aspects in palliative and end-of-life care in the United States](#)" and "[Assessment of decision-making capacity in adults](#)" and "[Intimate partner violence: Intervention and patient management](#)" and "[Physical child abuse: Diagnostic evaluation and management](#)" and "[Elder abuse, self-neglect, and related phenomena](#)".)

TERMINOLOGY

In this topic, “challenging” or “difficult” refers to specific interactions between health care providers and patients or family members that can range from awkward or uncomfortable conversations to life-threatening behaviors on the part of the patient or family members. There is substantial subjectivity regarding what constitutes a “difficult” interaction; a health care encounter experienced as difficult by one clinician may be welcomed by another as an opportunity to refine clinical skills.

There is neither a standard of care nor a definitive evidence base to guide the management of challenging interactions in palliative care settings. Most knowledge about this topic is derived from clinical experience, narrative reports, and extrapolation from small studies from other fields (eg, oncology; primary care). Nonetheless, psychological distress and conflictual interactions are common in seriously ill patients, and two related developments in palliative care (the provision of services earlier in the disease course and, increasingly, in ambulatory settings) highlight the relevance of this topic for clinicians.

There are few data on the frequency of challenging patient and/or family encounters in palliative care, but they seem to be as common as in the rest of health care [2], especially in the setting of intensive care decision-making [3]. In the United States, the complexity of modern health care contributes to the risk of medical errors and miscommunication [4]. Such “system issues” add to the stress levels of patients, families, and providers and increase the likelihood of difficult encounters. Despite the common occurrence of challenging interactions, most clinicians do not receive formal training in how to approach these situations.

CONTRIBUTING FACTORS TO CHALLENGING INTERACTIONS

Challenging interactions in the medical setting can be understood as interpersonal exchanges involving strong emotions such as anger, frustration, fear, despair, or humiliation. Associated behaviors include verbal outbursts, threats, destruction of property, or physical altercations. Extrapolations from general medical, oncology and primary care studies suggest that such interactions between patients and clinicians are both common (15 to 30 percent) and consequential [5-9].

Early reports focused almost exclusively on the characteristics of “difficult” or even “hateful” patients, who were described with labels such as obnoxious, demanding, clingy, entitled, angry, or disruptive [10,11]. More recent research suggests that difficult encounters are due to a complex set of factors that may additionally or alternatively reflect clinician factors or health care system failures [12]. Three main domains contribute to clinical encounters judged by both

patients and clinicians as problematic: patient characteristics, clinician characteristics, and health care system issues ([table 1](#)) [5].

GENERAL MANAGEMENT STRATEGIES

Recommendations for optimal patient interactions include [13]:

Communication

- Demonstrate basic professional manners, eg, try to be on time or come to the patient's room when you said you would, knock on the patient's door before entering, sit down whenever possible, ask permission to discuss sensitive subjects, and solicit questions after sharing information and recommendations ("What questions do you have for me?" rather than "Do you have any questions?").
- Be direct, clear, honest, and as specific as possible.
- Acknowledge limitations in a clinician's ability to predict treatment responses or outcomes.
- Provide consistent messaging about the plan of care and behavioral expectations of the patient (employ interdisciplinary team meetings, rounding as teams, and debriefing after behavioral incidents so as to promote consistent care plans).
- Minimize fragmented communication by designating a team member as a liaison, and try to limit changes in provider coverage and system complexity.
- Respond to challenging interactions in a matter-of-fact fashion (avoid pejorative language and name calling in the examination room, with colleagues, and in the medical record).
- Be explicit with patients about rules and behavioral expectations. For example, it may be necessary to state that physical threats or profane, offensive, and racist language will not be tolerated. Data are mixed with respect to the effectiveness of behavioral contracts [14]. Nonetheless, written rules and expectations can help minimize confusion and conflicts with patients.
- Be specific about how a particular behavior is problematic rather than making a general statement that the patient is difficult or behaving badly.

Other aspects of management

- Identify helpful family members and potential surrogate decision-makers as early as possible.
- Be mindful about countertransference, that is, the clinician's conscious and unconscious feelings and thoughts about the patient. (See ["Unipolar depression in adults: Psychodynamic psychotherapy"](#), section on 'Countertransference'.)
- Involve mental health specialists for consultation, either directly for patient care and/or to help the team respond to patient and family problems.
- Treat co-occurring mood or substance use disorders (SUDs) with targeted psychopharmacology and nonpharmacologic therapies following principles of symptom management and harm reduction.

Training to improve clinician communication skills — Several controlled trials have demonstrated the benefits of targeted training methods for palliative care clinicians. These approaches focus on improved communication skills regarding end-of-life care, recognition and management of difficult family emotions, improved methods of delivering bad news, and specific techniques to convey compassion [15-19]. Further discussions regarding clinician communication are found elsewhere. (See ["Communication of prognosis in palliative care"](#) and ["Discussing serious news"](#) and ["Cultural aspects of palliative care"](#).)

SPECIFIC CHALLENGING CLINICAL SCENARIOS

Personality disorders — Although there is virtually no research evidence about the most effective strategies for addressing patients with personality disorders in the medical setting, this is one of the most challenging clinical scenarios in palliative care. Individuals who struggle with trust, the need for control, or impulsivity are typically the most difficult patients for health care providers to care for. In this section, we specifically focus on patients with well-documented, longstanding, and clinically problematic personality disorders. We stress that all personality traits exist along a continuum and are not necessarily pathological. Nonetheless, stressful situations, such as life-limiting illnesses, promote vulnerability or intensification of maladaptive personality characteristics that may not be clinically apparent when the patient or family member is healthy [11].

Definition of personality disorders — Personality disorders are defined in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) as enduring, stable, and severe patterns of inner experience and behavior that markedly deviate from the expectations of the individual's culture [20]. These characteristics are typically present from adolescence or

young adulthood but become particularly problematic during periods of heightened stress, such as serious medical illness. Detailed descriptions for specific personality disorders are also listed elsewhere. (See "[Overview of personality disorders](#)".)

Recognizing personality disorders — Recognizing potentially challenging behaviors and personality disorders is important for several reasons: to initiate a plan for effective communication and treatment, to limit the risk of providing substandard care to the patient, and to establish realistic expectations for the health care provider.

Personality disorders can manifest in a variety of problematic behaviors, such as the following:

- Frequent demands for immediate care or specific treatment
- Nonadherence with treatment or follow-up care
- Rejection or refusal of recommended treatments
- Polarization of opinions about providers as either “good” or “bad” (ie, “splitting”)
- Hostility or aggression, including threats of assault or litigation
- Intimidation or devaluation of care providers
- Unmerited or inappropriate expectations about treatment or care
- Frequent requests for reassurance or demands for unnecessary medical interventions

We encourage clinicians to utilize a technique frequently employed by mental health providers: recognizing and describing the emotional reaction that the patient elicits in oneself. Patients who consistently engender strong negative emotional reactions in multiple providers may have personality traits that benefit from the management strategies listed in this section. This alone is inadequate to establish a diagnosis of a personality disorder but should rather serve as a prompt for the clinician to assess their interactions with the patient and modify their approach. Close attention to the patient’s psychosocial history can additionally provide clues about underlying maladaptive personality traits. An absence of substantive social ties or estrangement from most family and friends [21], a history of trauma or abuse [22], and/or multiple episodes of incarceration [23] suggest that the patient may have or be at increased risk for having a personality disorder.

Management approach — In addition to the guidelines outlined above (see '[General management strategies](#)' above), we endorse the following approach to the management of patients with known or suspected personality disorders [24]:

- Aim for clarity and consistency within the team regarding expectations and consequences. Regularly scheduled team meetings can facilitate this approach. In inpatient settings, it may be necessary for multiple providers to see the patient jointly. Proactive and frequent communication among treating team members (eg, the primary medical and nursing

team members, as well as involved consultants, social workers, case managers, etc) can reduce miscommunication and frustration for all involved.

- Adjust expectations; patients with personality disorders will typically require additional time and resources. For example, clinicians should allot extra time (again, with clear limits) when caring for these patients in both inpatient and outpatient settings.
- Elicit feedback from colleagues on your communication skills.
- Help diffuse tense interactions by demonstrating to the patient that you recognize their distress. However, clinicians should understand that empathic statements (eg, in response to the question “Isn’t there anything more you can do?”) might make matters worse (eg, with patients with borderline personality disorder who cannot control their emotions) [25].
- Ask patients to prioritize their agendas and focus on their most important concerns during meetings.
- Identify strategies to increase empathy for the patient. Prior to or after frustrating clinical encounters with the patient, we encourage providers to concentrate on specific aspects of the patient’s history or presentation that elicit compassion or at least sympathy. For example, a patient who is particularly anxious and demanding of certain accommodations may have experienced physical or sexual trauma. Patients with personality disorders can be extraordinarily frustrating, but their suffering is no less deserving of empathy than that of other patients. It may help to remind oneself not to take provocative remarks personally, but to try to understand them as a sign of the patient's distress.
- Consider involvement of the hospital ethics committee when the patient’s behavior or the providers’ responses lead to significant deviations in care or an inability to adhere to agreed-upon limitations.
- Familiarization with the basic principles of dialectical behavioral therapy (DBT) may also help clinicians more effectively approach and respond to patients with behaviors suggestive of borderline and narcissistic personality disorders. While a review of DBT is beyond the scope of this chapter, further information on psychotherapeutic techniques for borderline personality disorder can be found elsewhere. (See "[Borderline personality disorder: Psychotherapy](#)".)

Substance use disorders — Clinical interactions with patients who have substance use disorders (SUDs) and substance-induced disorders (eg, intoxication, withdrawal) are increasingly common in palliative care, particularly as palliative care is introduced earlier in the

illness trajectory and expands into ambulatory care settings. Nearly 20 percent of United States individuals aged 12 or older reported use of an illicit drug in the past year [26], and poisoning remains the leading cause of unintentional injury deaths [27].

SUDs represent a range of conditions resulting from the problematic use of 10 separate classes of substances (eg, alcohol, cannabinoids, opioids, benzodiazepines). SUDs may be classified as mild, moderate or severe; addiction, which is not a specific diagnosis in the DSM-5, is usually used to describe severe and compulsive drug seeking despite negative consequences [28]. SUDs are associated with a wide variety of problematic behaviors in the health care setting, which can range from inappropriate use of prescribed medications and demands for controlled substances to dangerous and criminal behavior ([table 2](#)). Left untreated, SUDs worsen prognosis and adherence to care [29,30]. In addition to complicating pain and symptom management, SUDs perpetuate patients' suffering and can create conflict with family supports and health care providers. Optimal care of patients who struggle with addiction requires a multidisciplinary approach with behavioral and psychopharmacologic expertise. General management of SUDs are discussed elsewhere. (See "[Management of acute pain in the patient chronically using opioids for non-cancer pain](#)" and "[Continuing care for addiction: Components and efficacy](#)".)

Barriers to optimal care — Despite the prevalence of SUDs, surveys of palliative care providers indicate that there is a need for better training in identifying and managing patients with addiction [27,31]. Unfortunately, many hospitals and outpatient clinics do not have dedicated SUD clinical programs. However, evidence suggests that palliative care providers' comfort with managing co-occurring SUDs may be improving. A review of the United States Medical Licensing Step Examination revealed the inclusion of multiple pain and symptom management question items assessing knowledge concerning SUDs [32]. A 2018 survey of North American palliative care providers reported evidence of improving confidence among palliative care clinicians in managing several aspects of chronic pain in cancer survivors [27].

There is no existing standard of care for screening and management of SUDs in palliative care. In ambulatory palliative care clinics, routine screening for SUDs among patients and family members is variable, with most providers reporting that screening occurs when the provider feels it is appropriate [33]. A survey of United States Medicare-certified hospices revealed that 68 percent included substance use in their psychosocial assessments, but these screening questions lacked standardization or detail [34]. Existing data suggest that many palliative care and hospice programs are inadequately prepared or resourced to assess or manage patients with aberrant behaviors or evidence of drug abuse [35,36]. Most opioid risk screening instruments, such as the Screener and Opioid Assessment for Patients with Pain (SOAPP;

SOAPP-Revised [SOAPP-R] or SOAPP-Short Form [SOAPP-SF]) or the Opioid Risk Tool (ORT), have not been validated for the palliative care population [37,38]. Further complicating SUD assessment and management in palliative care is the discordant legal status of [medical cannabis](#) across state and federal governments paired with patients' increased use of both medical and recreational cannabis for symptom management [39]. (See "[Opioid use disorder: Epidemiology, clinical features, health consequences, screening, and assessment](#)" and "[Cancer pain management: General principles and risk management for patients receiving opioids](#)", section on 'Risk assessment and management for patients receiving opioids'.)

Management — We endorse the following approach for patients at risk for or suspected to have SUDs, particularly those who present for outpatient palliative care services:

At the beginning of treatment

- Identify a single prescriber for high-risk medications, such as opioids, stimulants, and benzodiazepines.
- Conduct an opioid risk assessment with all ambulatory patients. The ORT [40] and SOAPP-R [41] are two publically available options.
- Establish with the patient and family shared goals and expectations of pain and other symptom management (eg, "0 out of 10 pain" is rarely a realistic goal).
- Before dispensing medications, provide clear (verbal and written) expectations and limits regarding early refills, unsanctioned dose escalations, missed appointments, and lost prescriptions.
- For patients with moderate or severe SUDs, expect and plan for relapse. Prior to lapses in treatment adherence or return to substance use, identify what, if any, consequences will occur if patients do not comply with expectations.

During treatment

- For patients with chronic pain who show aberrant drug-related behavior, a brief behavioral intervention (close monitoring, monthly urine screens, cognitive behavioral counseling) might increase overall adherence with the care plan [42].
- Otherwise, we do not recommend systematic urine drug screening unless the provider has a clear plan for how to respond to positive toxicology testing.

- Employ frequent clinic visits, and dispense prescriptions in one- to two-week intervals. Although these steps can be inconvenient, they are often necessary for at-risk patients.
- Coprescription of [naloxone](#) for patients with elevated risk of opioid overdose: exposure to opioid doses ≥ 50 [morphine](#) milligram equivalents/day, concomitant use of benzodiazepines, and prior history of SUDs or overdose [43]. Naloxone distribution is linked to reduced rates of opioid-related fatal overdose [44]. Patient counseling and education about proper use should accompany prescription.
- At each visit, review patient data from state-sponsored prescription monitoring programs (where available).
- Maximize use of non-habit-forming medications and nonpharmacologic treatments.
- Refer to addiction specialists if problems are severe and persistent.
- Consider transitioning selected patients with opioid addiction and pain disorder (ie, highly motivated and adherent) to [buprenorphine](#), an office-based opioid maintenance treatment that is associated with a decreased risk of relapse in patients who are opioid dependent [45]. Buprenorphine, a schedule III agent, requires a specific Drug Enforcement Administration (DEA) license to prescribe (see "[Cancer pain management with opioids: Optimizing analgesia](#)" and "[Opioid use disorder: Pharmacologic management](#)"). [Methadone](#), a schedule II opioid, may effectively treat pain disorders. If used for the treatment of concomitant addiction (eg, medication-assisted therapy for opioid use disorders), however, its use is restricted to federally regulated opioid treatment programs.

Suicidality — Suicidal patients can elicit discomfort in palliative care clinicians, who may feel inadequately trained to evaluate and treat these challenging patients [46-48]. Suicidality in seriously ill patients may take the form of passive thoughts of death, specific plans to end one's own life, requests for physician-assisted or hastened death [49,50], or deliberate self-injurious behavior (eg, intentional overdosing with narcotics, attempted and completed suicides). (See "[Medical aid in dying: Ethical and legal issues](#)".)

Suicidal ideation and behavior and requests for physician-assisted death are common in cancer and other life-limiting illnesses:

- In a study conducted in oncology clinics in the United Kingdom, roughly 8 percent of outpatients with cancer endorsed the suicidal item on the Patient Health Questionnaire 9 (PHQ-9) depression screening instrument ([table 3](#)) [51].

- The completed suicide rate in patients with cancer is twice the rate in the general population [52], and it is highest in the first few months after a cancer diagnosis [53,54].
- Adolescent and young adult patients with cancer appear to be at increased risk for suicidal ideation and completed suicides [55,56].
- Risk of suicidal behavior is significantly higher than in the general population for most medical illnesses [54,57].
- A 2018 Veterans Administration cancer registry study of patients with advanced lung cancer reported a decreased risk of death by suicide in patients who received palliative care [26].

Management approach

- Suicidal comments may reveal a patient's specific plan to take their life. Consequently, clinicians must respond immediately. The patient should be asked explicitly about current suicidal thoughts, plans, and access to lethal means (eg, firearms, stockpiled medications).
- Urgent referral to a mental health professional or the emergency department is indicated for acute suicidal threats (eg, high intent with a plan, or a specific plan with high lethality) or the inability of the patient to assure their safety. We no longer ask patients to "contract for safety" because there is little evidence that it works. Rather, we suggest that clinicians discuss a safety plan that specifies how patients can cope with recurrent suicidal urges in the future ([figure 1](#)). (See "[Suicidal ideation and behavior in adults](#)", [section on 'Safety plan'](#).)
- A suicidal statement is often an expression of distress, pain, fear, loss of control, or worry about becoming a burden to loved ones. In these cases, the most helpful approach is to explore the underlying distress and meaning of the statement. Patients should be reassured with respect to effective symptom management and the health care team's commitment to the patient's preferences and values. Referral for mental health counseling and evaluation for pharmacotherapy for a comorbid psychiatric disorder should be considered.
- A survey of 93 young adults with advanced cancer revealed an association between having a strong patient-oncologist alliance and a lower risk of suicidal ideation [58]. This finding suggests that palliative care clinicians are well positioned to manage and potentially reduce the likelihood of suicidality in patients with advanced disease.

Dangerous behavior/violence — A review of the growing problem of workplace violence for health care workers in the United States suggested that acts of violence toward health care providers are more common than generally appreciated [59,60]. To our knowledge, there are no systematic studies of violence directed at palliative care clinicians. Anecdotally, verbal threats by patients or family members are most commonly related to miscommunication, the receipt of bad news, adverse medical outcomes, and demands for opioid and benzodiazepine prescriptions.

Additionally, palliative care scenarios associated with threats of violence or assault often include cases of altered mental status [59], for example:

- Neurocognitive disorders
 - Dementia (and other major neurocognitive disorders)
 - Delirium
- Substance intoxication
- Decompensated mental illness

Signs of potential impending physical violence include:

- Increased voice volume and harsh tone
- Threats of various types
- Erratic, impulsive, or agitated behavior
- Expressions of paranoia or other delusional thinking

Management approach

- Ensure adequate staffing and a safe clinical environment (eg, availability of additional personnel, if needed; arrangement of furniture in the interview room so that the clinician sits closest to the door).
- Communicate your respect for the patient while being firm, clear, and calm in your response to an escalating or agitated patient.
- Do not tolerate threats or verbal abuse as this may be associated with escalating behavior.
- Provide patients with clear expectations regarding unacceptable behavior with health care system staff.
- Consult mental health specialists for a safety evaluation when patients make threats or demonstrate escalating problematic behaviors.

- Implement a “behavioral response code” that involves hospital police or security.
- More specific recommendations on the management of violent patients are provided elsewhere. (See ["Assessment and emergency management of the acutely agitated or violent adult"](#).)

Refusal of care — A common challenge for palliative care providers occurs when a patient or family member ignores, resists, or refuses recommended care ([table 4](#)). In this section, we focus on interactions in which patients expressly communicate their unwillingness to accept health care providers’ clinical recommendations. Further discussion with respect to patient adherence to care is a broader topic covered elsewhere. (See ["Psychological factors affecting other medical conditions: Management"](#) and ["Psychological factors affecting other medical conditions: Clinical features, assessment, and diagnosis"](#).)

Since palliative care patients are seriously ill and receive medications that affect the central nervous system, the first priority is to determine if the patient has decision-making capacity. (See ["Assessment of decision-making capacity in adults"](#).)

Depression may underlie a patient’s refusal of care, highlighting the need for careful evaluation of depressive symptoms. In a study of medical inpatients over 65 years of age including 50 depressed subjects and 50 nondepressed controls, depressed subjects desired fewer interventions than control subjects, both in their current health as well as in hypothetical situations with good prognosis [61].

The incapacitated patient who is accepting of care raises interesting clinical and ethical questions but does not typically prompt concerns from clinicians or family members and will not be discussed here.

Management approach — Patients who possess decision-making capacity are legally and ethically permitted to refuse medical care. An approach to assessment of decision-making capacity, modified from the Appelbaum framework [62], is outlined in the table ([table 5](#)) and addressed in detail elsewhere. (See ["Assessment of decision-making capacity in adults"](#) and ["Legal aspects in palliative and end-of-life care in the United States"](#).)

For those who lack decision-making capacity, medical care to restore capacity should be attempted whenever possible. In general, forced treatment over the patient’s objection (authorized by a surrogate decision-maker) in an incapacitated patient could be considered for a one-time or short-term intervention (eg, procedures to lessen pain, improve breathing, or alleviate a bowel obstruction) but should be avoided for repeated interventions that require a high degree of patient cooperation (eg, indefinite dialysis or chemotherapy for several weeks).

(See ["Assessment of decision-making capacity in adults"](#), section on ["What to do when a patient lacks capacity"](#).)

Family-specific issues — Life-limiting illness and death have a significant impact on family systems and their functioning. Increasingly, family members are expected to take on substantial caregiving responsibilities in chronic illness and at the end of life. These expectations often occur without adequate training or preparation and pose significant financial, mental, and physical health burdens [63-65]. In modern health care, the proliferation of treatment options also means that families are asked to participate in complex medical decision-making at the end of life. It is unsurprising that serious illness and death can create a high-stress environment for most family members and highlight or renew difficult family dynamics. In particular, transitions of care when there is an acute decline in the patient's functioning can precipitate greater family distress [66]. In a United States qualitative study of 37 families of patients with advanced lung cancer, 65 percent of families reported conflict about the patient's care [67]. The psychological consequences of caregiver responsibilities and substitute decision-making are substantial; in a 2001 study of 920 family caregivers of patients hospitalized in an intensive care unit, the prevalence of clinically significant anxiety and depression symptoms was 69 and 35 percent [68].

Family conflict at the end of life can interfere with the provision of optimal patient care, a source of frustration for providers and caregivers alike. There may be distortions in communication or understanding of prognosis and the anticipated benefits and risks of treatment [69]. Further, these conflicts can create delays in decision-making or receipt of care, promote care that is discordant with the patient's goals, and increase caregiver distress, particularly when the patient has not previously specified their goals of care [70]. (See ["Unipolar depression in adults: Family and couples therapy"](#).)

Common sources of family conflict

- The perception or belief that a family member is providing insufficient help or care [71].
- Disagreement (between family members, the patient and family members, health care providers and family) regarding the nature of the patient's illness and prognosis, the patient's needs, the treatment, or the plan of care [72].
- Disagreements by family members about the patient's care preferences.
- Multiple family members involved with clinical decision-making.
- Surrogate decision-makers not using substituted judgement to guide the patient's care.

- Only episodic involvement, or nonengagement of families with the patient's care.
- Distrust of medical care, the health care system, or health care providers.
- Cultural and religious differences between the patient (or family) and the health care provider.
- Reactivation or intensification of longstanding family conflict or problems unrelated to the patient's illness or situation.
- Inaccurate assumptions (by the family or health care providers) about health care power of attorney and guardianship matters.
- Different grief trajectories, with some family members being more accepting and others less so of the approach of death or other potential negative outcomes.

General management strategies — Several strategies are broadly beneficial when family conflict arises. Not surprisingly, the best approach for reducing family conflict at the end of life is to improve family communication and functioning prior to an acute conflict or crisis. Providers must be sensitive to the diverse experiences and backgrounds of patients and their families. Clear communication about end-of-life goals and preferences between the patient and family can reduce the likelihood of confusion or conflict. However, by the time palliative care specialists have been consulted, the optimal moment for this approach may have passed.

We also recommend initiating early and frequent family meetings. When possible, the initial family meeting should focus on understanding the family system and individual members, rather than pressing to make specific decisions. Follow-up meetings can then focus more on consensus and shared decision-making [73]. Below, we discuss several additional common scenarios. (See ['Conflict between the patient and family or among family members'](#) below and ['Disagreements between family members and the treatment team'](#) below and ['Family decision makers with questionable decision-making capacity'](#) below and ["Communication in the ICU: Holding a meeting with families and caregivers"](#).)

Conflict between the patient and family or among family members — Conflicts within families that affect patient care are unique to each family and must be addressed on a case-by-case basis. When the patient is incapacitated, familial conflict about decision-making can lead to prolongation of dying or provision of care discordant with the patient's wishes [74]. When conflict within families interferes with the patient's care, we encourage:

- Clarifying whether the patient possesses decision-making capacity.

- Exploring the patient's preferences regarding decision-making and whether the patient prefers an individualized or family-based approach. Guidelines exist for addressing issues of cultural diversity at the end of life [75]. Further discussion regarding the cultural aspects of palliative care is found elsewhere. (See "[Cultural aspects of palliative care](#)".)
- Differentiating health care-related family conflict from broader family dynamics.
- Involving patient advocates in discussions when there is concern that the patient's autonomy or ability to openly communicate is compromised by family members.

Family decision-making is a complex process involving both explicit discussions and implicit communication based on prior family interactions. To help clarify these dynamics, clinicians can ask families to discuss their previous medical decision-making experiences with respect to:

- Their specific roles in the family (for example, is there typically a single decision-maker or a consensus-based approach?)
- Family-held values (eg, patient comfort, honoring previously expressed wishes, faith-based priorities)
- How the family copes with differences in opinions about major decisions
- Whether or how the absence of the patient's ability to directly contribute to decision-making affects their previously established decision-making processes

Disagreements between family members and the treatment team — Conflicts between family members and health care providers are not uncommon, particularly when addressing emotionally laden topics, such as decisions about a critically ill family member. In a study of decisions to limit life-sustaining treatments in the medical intensive care unit, researchers identified disagreements between health care providers and family members over the treatment decision in 33 percent of the cases [3]. When disagreements between providers and family members do occur, we recommend the following considerations in addition to the steps outlined above (see '[General management strategies](#)' above):

- Recognize personal feelings of anger, fear, or frustration so that these emotions do not unduly influence communication with family members.
- Identify the source of the conflict, whether it is due to true differences of opinion about the nature of the patient's illness or treatment, breakdowns in communication, personality or cultural differences, and/or unaddressed emotional issues [3].

- When discussing withdrawal of life-sustaining treatments, directly explore family members' feelings of guilt or remorse. For example, if a family member states, "I know my father would not want this, but I just can't let him go" or "I can't make a decision that results in his death," the clinician can respond with a reflective statement and further exploration: "I imagine it is extremely difficult to make a decision in this situation. Some families say they do not want to be responsible for a decision because it can be so hard. We see this as a shared decision, just as it would be if your father was able to have this conversation with us."
- Explore the relationship of the patient to the family members who are experiencing heightened distress to allow emotions, especially grief, to emerge (eg, "Tell me about your mom... what would you miss most about her if she does not survive?").
- Assess whether a premorbid history of family conflict exists.
- Utilize strategies common in bioethics mediation [76]; a step-wise approach to addressing conflict involving family members has been described [77].

Family decision makers with questionable decision-making capacity — When a patient is unable to make decisions about their health care, a designated surrogate, typically a family member, assumes authority and responsibility for the patient in the informed consent process. Further information on assessing decision-making capacity and on what to do when a patient lacks capacity is presented elsewhere. (See "[Assessment of decision-making capacity in adults](#)".)

The decision-making capacity of the surrogate may also be questionable, however, due to their own cognitive capacity, comorbid psychiatric illness or addiction, conflicts of interest, or inability to act using either the standards of substituted judgment or the best interests of the patient. The team may have concerns that the surrogate is making decisions based on their own personal values and preferences instead of the patient's [78]. In these scenarios, we suggest the following:

- Explore the surrogate's grief, which is a common factor in unrealistic expectations and demands for aggressive and nonbeneficial care. (See '[Disagreements between family members and the treatment team](#)' above.)
- Involve the hospital ethics consultant or committee.
- Engage the surrogate decision-maker in a multidisciplinary meeting with the team leader, key clinicians, the ethics consultant, and other potential surrogate decision-makers.

- Educate the surrogate decision-maker on their roles and expectations, including how substituted judgment differs from a “best interest” approach. (See ["Legal aspects in palliative and end-of-life care in the United States"](#).)
- If the ethics consultant/committee and the health care team believe that an alternative surrogate decision-maker is needed, then involve risk management.

SOCIETY GUIDELINE LINKS

Links to society and government-sponsored guidelines from selected countries and regions around the world are provided separately. (See ["Society guideline links: Palliative care"](#).)

SUMMARY AND RECOMMENDATIONS

- Patient characteristics, provider factors, and health care system issues can each contribute to challenging encounters in palliative care. (See ['Contributing factors to challenging interactions'](#) above.)
- During challenging patient and family interactions, providers should prioritize communication, negotiation, and consensus building. (See ['General management strategies'](#) above.)
- Providers should recognize their own emotions, attitudes, and behaviors toward challenging patients and their families to provide more effective care during difficult clinical encounters. (See ['Other aspects of management'](#) above.)
- Aim for consistency, clear expectations, and treatment team consensus on the consequences for patients and families who are unable or unwilling to adhere to expectations. (See ['Specific challenging clinical scenarios'](#) above.)
- Stressful situations, such as life-limiting illness, promote intensification of maladaptive personality characteristics that may not be apparent when the patient or family member is healthy. Recognizing potentially challenging behaviors and personality disorders is important in order to initiate a plan for effective treatment, limit the risk of providing substandard care to the patient, and establish realistic expectations for the health care provider. (See ['Personality disorders'](#) above.)
- For patients at risk for or suspected to have substance use disorders (SUDs), our approach includes identifying a single prescriber for high-risk medications (eg, opioids and

benzodiazepines) and establishing clear goals and expectations regarding pain and other symptom management, limits regarding early refills, lost prescriptions, etc. (See ['Substance use disorders'](#) above.)

- Providers must be sensitive to the diverse experiences and backgrounds of patients and their families, particularly with regard to end-of-life care. (See ['Family-specific issues'](#) above.)

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