

# Make the Call: Engaging Family as a Critical Intervention

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“Is there anyone you’d like us to call?” the admitting physician asked. Ms. A thought for a moment before replying, “No, thanks,” and the physician continued outlining the next steps. She had just learned the news: masses in her lungs, spine, and liver, almost certainly metastatic cancer. Scans also showed bilateral pulmonary emboli. A previously healthy and independent 65-year-old woman with hypertension, Ms. A had been sent to the emergency room directly by her primary care physician for hypoxia after presenting with fatigue and shortness of breath for several weeks. Now admitted, she was started on anticoagulation and scheduled for a biopsy while her chart read “family – declined contact.” Her respiratory status gradually worsened over several days, and, ultimately, she was transferred to the intensive care unit (ICU). By the time pathology confirmed that the masses were indeed lung cancer, she was too sick to receive cancer-directed treatment and palliative care was consulted. At that point, Ms. A shared that she had two adult children, whom she had not wanted to burden about her hospitalization given their own health issues. Realizing the gravity of her illness, she finally agreed she would want her family informed and present, so a palliative care team member helped her make the calls. Shocked, both children were on the next plane to visit, with sobs and clenched hands marking their palpable grief. Ms. A died in the ICU two days after her children arrived.

This scenario is not uncommon: a patient is diagnosed with a serious illness and declines to include anyone in conversations with clinicians about their care. Delays in engagement can cost both patients and families dearly (with “family” used hereafter as an all-encompassing term for the people a patient identifies as important, irrespective of traditional definitions). For the patient, late family involvement leads to less time for meaningful activities, from spending time with loved ones to life review projects to spiritual or religious end-of-life rituals. It also means less time for planning the practical aspects of death (finances,

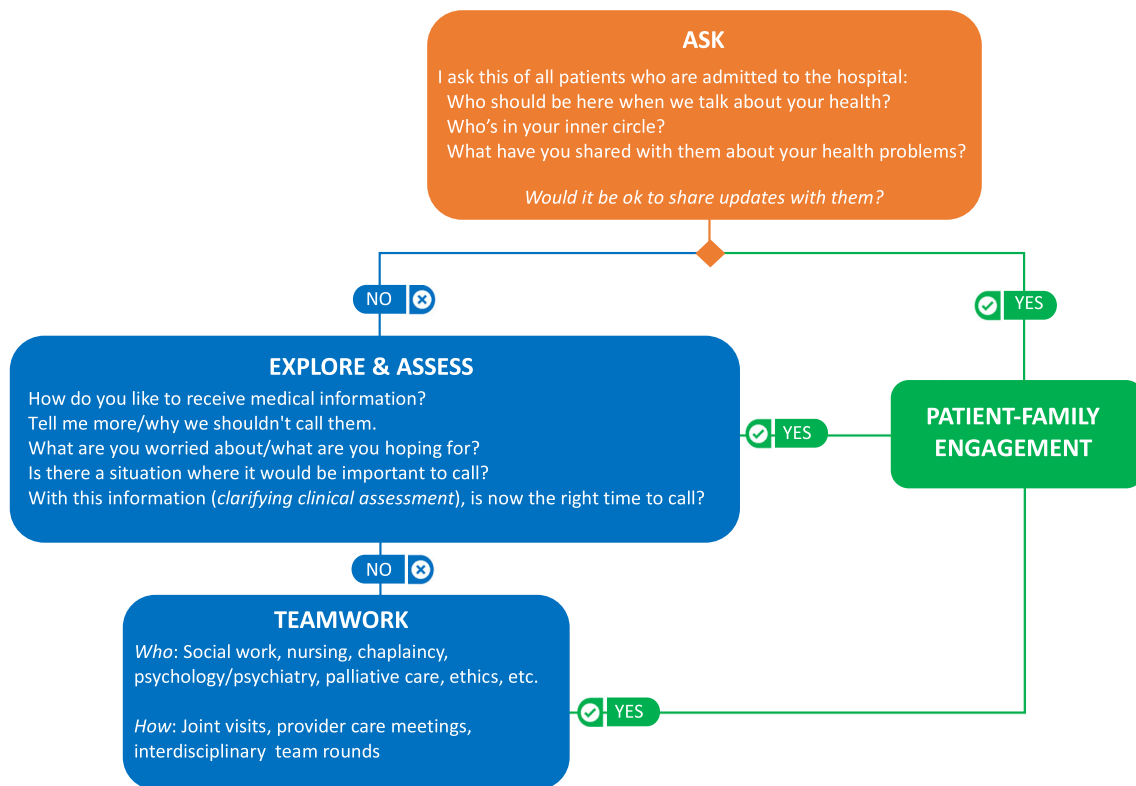
estate, funeral/memorial requests, etc.), which can be critically important to patients and their survivors. Patients often rely on families when making medical decisions, but families are not able to participate in that process if they are not involved. Moreover, given that 70% of older patients who require medical decision-making prior to death also lack decision-making capacity, family are likely to be asked regardless.<sup>1</sup> By not including them, we place those patients at an increased risk of becoming unrepresented if contact information is unknown and not receiving goal-concordant care. Last, families themselves also suffer: families find communication regarding prognosis to be unsatisfactory when the patient is imminently dying, and are more likely to experience symptoms of post-traumatic stress disorder when they feel unheard in an ICU.<sup>2, 3</sup> Ms. A and her family faced every one of these negative consequences. Not only was her time with loved ones traumatically cut short, she was also not able to discuss her end-of-life preferences nor complete key financial planning for her children, leaving them uncertain about her wishes.

When a clinician invites a patient to include their family in their care, rather than taking a “no” at face value, they can take the opportunity to learn more about a patient’s reasoning, the same as if the patient were to decline a biopsy or a course of antibiotics. Qualitative studies looking at communication between family and patients with late-stage cancer show a majority are hindered by avoidance of distress, attempts to be mutually protective, and positive thinking—all dynamics that can be clinically relevant and merit further exploration.<sup>4</sup> In our case, by exploring with Ms. A and discovering her reluctance came from concerns for her children’s wellbeing, the palliative care team was able to recommend that given her illness severity, this would be an important time to include them. This is consistent with literature on prognostic understanding affecting a patient’s ability to self-initiate conversations, as patients who know they have a life-limiting illness are more likely to discuss care preferences with family.<sup>5</sup> Although clinicians might feel uneasy recommending the inclusion of family when told no, the ethics of persuasion highlight its use in these moments as a positive influence if in alignment with the patient’s goals.<sup>6</sup> To be sure, certain circumstances preclude this inclusion, such as safety concerns (physical, psychological, financial) or social isolation. Understanding the reasoning behind a “no” can identify these important details and trigger additional support from social work, palliative care, and/or ethics.<sup>7</sup>

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**Figure 1** Practical tips on how to engage a seriously ill patient and their family in communication.

We suggest a structured approach to engaging families in the care of seriously ill patients (Fig. 1). Note that this approach assumes the patient has medical decision-making capacity. First, ask who should be involved in shared decision-making and normalize this ask. If a patient declines to involve anyone, rather than taking this at face value, use it as an opportunity to explore further. Who is in their inner circle? How often do they keep in contact? What are their concerns about sharing their diagnosis and/or prognosis? This step involves understanding a patient's preferences on receiving medical information and how they make decisions. The answers to these questions help the clinician assess how and when it is appropriate to contact family in an iterative, active process. It can also lay the groundwork for serious illness communication and/or transitional care planning. Last, if despite ongoing attempts at this process the patient still declines to include family, the clinician should involve other members of the interdisciplinary care team, such as a chaplain, social worker, and/or nurse. These clinicians offer unique skillsets and diverse perspectives that can enhance communication and patient care. In challenging cases, we also recommend consulting palliative care for support of the patient, family, and clinicians.

The emotional turbulence of engaging family in the context of serious illness, especially when a patient is reluctant, is often a barrier to a clinician attempting it. However, incorporating families into the care plan is critical as patients rely on their family members to cope emotionally and plan for the future. Making the call to include them, and explore past the reluctance, should always be at the top of our to-do list.

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**Declarations:**

**Conflict of Interest:** None.

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