



HHS Public Access

Author manuscript

Am Soc Clin Oncol Educ Book. Author manuscript; available in PMC 2021 March 01.

Published in final edited form as:

Am Soc Clin Oncol Educ Book. 2020 March ; 40: 1–11. doi:10.1200/EDBK_280279.

Medical decision-making in oncology for patients lacking capacity

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Abstract

Modern oncology practice is built upon the idea that a patient with cancer has the legal and ethical right to make decisions about their medical care. There are situations in which patients might no longer be fully able to make decisions on their own behalf, however, and some patients never were able to do so. In such cases, it is critical to be aware of how to determine if a patient has the ability to make medical decisions and what should be done if they do not. Here, we examine the concept of decision-making capacity in oncology and explore situations in which patients may have altered/diminished capacity (e.g., depression, cognitive impairment, delirium, brain tumor, brain metastases, etc.) or never had decisional capacity (e.g., minor children, developmentally disabled adults). We describe fundamental principles to consider when caring for a patient with cancer who lacks decisional capacity. We then introduce strategies for capacity assessment and how clinicians might navigate scenarios in which their patients could lack capacity to make decisions about their cancer care. Finally, we explore ways in which pediatric and medical oncology can learn from one another with regard to these challenging situations.

TWEET:

Patients w/ #cancer sometimes lack capacity to make decisions about their medical care. How best to navigate these complex, stressful cases?

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Introduction

Medical decision-making is a core component of the care of patients with cancer. Each clinic visit and inpatient encounter includes many individual medical decisions—about treatment options, symptom management, potential clinical trial enrollment, and numerous other aspects of care. Modern medical practice places great emphasis on an individual’s right to self-determination, to choose what is or is not done to them. This is often discussed in reference to the principle of autonomy.¹ There are situations, however, in which patients may no longer be able to make decisions on their own behalf. In oncology, this could be as a result of their underlying cancer diagnosis, treatment-related sequelae, and/or unrelated issues. Further, some patients never were able to make autonomous decisions, such as minor children and those with severe neurodevelopmental disorders. In all cases, it is critical to understand how to determine if a patient has *decisional capacity*: the ability (legally, ethically, and otherwise) to make medical decisions. Here, we will examine how a patient’s decisional capacity can be assessed and discuss various situations in which patients with cancer might lack full capacity.

Decisional Capacity in Oncology

Patients must have decisional capacity to make ethically and legally valid medical decisions.² From an ethical perspective, the requirement for decisional capacity reflects both a desire to protect the rights of capable patients to make their own choices and the imperative to protect incapable patients from the consequences of decisions reached without adequate mental capacity. These dual concerns are also reflected in law: decisions made by incapable persons are not legally valid, whether they relate to medical treatment or other matters, including contractual agreements, wills, or marriage. When a patient is deemed incapable, a surrogate must be sought, in accord with state law, to make medical decisions in the patient’s place. A corollary of the invalidity of decisions by incapable patients is that physicians can be held liable for the adverse consequences of treatment undertaken without a competent consent.*

Thus, there are multiple reasons for oncologists and other physicians to be aware of the possibility of impaired decision making by their patients, to know how to assess decisional capacity, and to be prepared to utilize surrogate decision makers when indicated. Rates of incapacity in hospitalized patients with a range of diagnoses are high, with one British study finding 48% of medical inpatients to lack capacity.³ Problems with capacity are not limited to the inpatient setting. A study of oncology outpatients using a structured competence assessment tool found almost one-third did not have capacity to consent to a research study, with lower education, greater age, and deficits on neuropsychological testing predictive of impaired performance.⁴ One-quarter of neuro-oncology patients were judged to lack capacity to consent to neurosurgical procedures,⁵ one-third of malignant glioma patients showed some degree of impaired capacities for research consent,⁶ and 60% of patients with

* A note on terminology: although suggestions have been made to distinguish “capacity” and “competence”—with the former often taken to encompass medical determinations and the latter judicial decisions about a person’s decision-making abilities—we use the terms here interchangeably. This reflects the lack of consistent distinctions between the terms in caselaw and statutes, as well as in the medical community.

brain metastases were found not to have competence for treatment decisions.⁷ However, physicians often fail to detect incompetence in their patients. In the British study of medical inpatients, for example, only one-quarter of incompetent patients had been identified as lacking capacity by their treatment teams,³ and among the neuro-oncology patients approximately half of those lacking capacity had not been detected.⁵

Defining Decisional Capacity

Three characteristics of decisional capacity are essential to understanding the nature and scope of its assessment.² First, capacity is domain-specific. Although historically persons were deemed globally competent or incompetent, the modern approach recognizes that capacity may vary depending on the type of decision with which someone is faced. A patient with a focal delusion about his or her physician may lack capacity to make a treatment decision, while being perfectly competent to make a decision about investments. Second, capacity is task-specific. Even within a given domain, e.g., medical decisions, a person with impaired decisional abilities may retain capacity for simpler decisions—such as receiving a flu vaccine—while lacking capacity for more complex ones—such as deciding among approaches to the treatment of metastatic cancer. Third, capacity is temporally-specific. Decisional abilities fluctuate with changes in mental state related to such variables as electrolyte balance, oxygenation, delirium, pain, and anxiety.

Thus, capacity assessments are of necessity about a specific decision, with a given degree of complexity, at a single point in time. Conclusions about capacity may change as any of these factors is altered. Within that context, generally accepted legal and ethical standards for capacity (with only modest variation across jurisdictions) fall into four categories: understanding, appreciation, reasoning, and communicating a choice (TABLE 1).^{8,9} Although competence is ultimately a legal matter that can be subject to adjudication, caselaw and statutes recognize that in most instances such determinations should be made in the clinical setting, lest treatment be delayed and the courts overwhelmed with such cases.

Assessing Decisional Capacity

All physicians should be prepared to assess their patients' decisional capacity, given that competence is a requirement of valid consent. Complex cases may need to be referred to a specialist—consultation/liaison (CL) psychiatrists¹⁰ and ethics consultants¹¹ are frequently called on for such evaluations. Although implicit assessments of patients' competence probably occur during every physician-patient interaction, when doubt exists about a patient's capacities and a more formal evaluation is called for, two preliminary steps should be undertaken. First, the patient should be informed of the purpose of the evaluation, both as a matter of fairness and to give the patient an opportunity to maximize his or her performance; however, an explicit consent to be evaluated is not required. Second, the examiner should ascertain that the patient has been fully informed of the information relevant to the treatment decision in question. That is most easily done by redisclosing the key information required for informed consent at the time of the evaluation. Doing that eliminates ambiguity associated with whether the patient remembers what he or she was told

at some point in the past and allows the evaluator to look for signs of comprehension or confusion.

Having a fixed structure for the evaluation is likely to result in more reliable competence determinations.¹² Assessment should begin with a review of the patient's general mental status and history, if any, of psychiatric or neurologic disorders. The evaluator can then move to a direct assessment of capacity for the decision at hand. Simple questions designed to embody the four components of competence are available in the medical literature and can facilitate this process.⁸ For more complex cases or circumstances in which court proceedings are likely, use of an assessment instrument may be helpful in structuring and documenting the evaluation, as well as reliably quantifying the degree of impairment.^{13,14} Information from a patient's family members, close friends and nursing staff can be helpful in identifying impairments that may not be detected on direct evaluation (perhaps because of fluctuations in the patient's condition) and in clarifying whether they represent stable or evolving characteristics of the patient.

No algorithm exists for determining whether a patient's capacities are sufficient for the decision with which the person is faced—the ultimate purpose of the evaluation. It is generally accepted that the greater the complexity of the decision and the higher the risk associated with the patient's choice, the greater degree of capacity that is required.² This is sometimes referred to as a “sliding scale” approach.¹⁵ When a formal assessment instrument is used, published data may allow comparison of the patient's performance with that of other patients. It is important to recognize that law and ethics presume a patient is competent to make treatment decisions until proven otherwise. Thus, sufficient evidence must exist to rebut that presumption before declaring a patient to lack capacity. Whenever possible, inquiry should be made into the cause of patients' impairments and, if treatable, interventions should be undertaken to restore the patients' abilities to make decisions for themselves. We provide here (FIGURE 1) a model framework for identifying patients with cancer with an elevated risk of having diminished decisional capacity, assessing capacity, and acting based on that assessment. This framework should be seen as a guide, however, and may not be applicable to all patients/scenarios.

Considering capacity in the context of other comorbidities

Alterations in cognition can be observed in patients with cancer and may be related to a variety of factors including the nature of the cancer itself, a consequence of cancer-directed therapy, or related to underlying comorbid conditions. Cognitive decline can potentially influence capacity, depending on the degree to which cognition is affected, the underlying cognitive reserve, and the relevant context of the situation (i.e., the complexity of the decision at hand). Certainly, cognitive changes do not necessarily equate with a decline in decisional capacity, but cognition is an important and relevant aspect when considering capacity.

Cognitive changes related to cancer and/or cancer therapy

Cancer-related cognitive decline can be secondary to the cancer itself, either primary disease or metastases. Brain tumors can result in destruction and infiltration of brain tissue, inducing

cognitive changes, and some high-grade central nervous system (CNS) tumors are especially associated with precipitous loss and lack of capacity.¹⁶ For example, one study demonstrated that more than 50% of patients with malignant gliomas exhibit compromised capacity, compared to non-cancer controls.¹⁷ Cognitive measures of verbal memory are associated with capacity impairments in this population, with reduced performance on appreciation, reasoning and understanding standards. As many as 90% of these patients lack capacity in the final days prior to their death.^{16,18} Further, 90% of patients with non-primary CNS tumors with brain metastases exhibit some cognitive impairment even prior to treatment. Volume, rather than number, of metastatic lesions correlates with degree of impairment. Over half of patients with brain metastases have reduced capacity to make treatment decisions (defined as performance 1.5 standard deviations below the non-cancer control group).¹⁹

There has been extensive research in the area of cancer-related cognitive dysfunction (CRCDD), commonly referred to as “chemo brain.” However, the majority of patients enrolled in clinical trials evaluating CRCDD have been younger patients without pre-existing cognitive impairment, and the cognitive changes are usually described as more mild, and thus relatively unlikely to be detrimental to decision-making capacity,^{20–22} although capacity has not been explicitly evaluated in these studies to date. Radiation therapy to the central nervous system has demonstrated the potential to incite more pronounced and longer-term memory impairment, with some 50–90% of survivors exhibiting “disabling cognitive dysfunction,” though such studies have not observed direct deterioration leading to incapacity.²³

Cognitive changes related to pre-existing comorbidities

In the older adult population, it is important to consider the presence of a pre-existing cognitive impairment, such as mild cognitive impairment or dementia, in the context of capacity. Older adults have a higher prevalence of independently occurring dementia as compared to younger patients. A study of community-dwelling older adults (age 70 and over) without cancer demonstrated that nearly 1 in 4 had signs of cognitive impairment without dementia, with approximately 12% of these patients annually progressing to dementia.^{24–26} In older adults with cancer, SEER Medicare analyses suggest an estimated prevalence of dementia in 3.8 to 7% of patients, although this may be an underestimate given that cognitive screening is not typically performed in the oncology setting and these large datasets may not accurately capture all diagnoses.^{27–30} Pre-existing cognitive impairment may influence the potential risks and benefits of cancer therapy, thus increasing the complexity of decisions about cancer management for this population and reinforcing the importance of assessing decisional capacity. Even milder forms of abnormal cognition may influence decisional capacity. In one informative study, 45 patients with cancer were evaluated and presented with descriptions of a randomized controlled trial along with an Institutional Review Board (IRB)-approved consent form.³¹ Investigators identified that abnormal tests of cognitive function (such as inability to spell WORLD backwards [an item from the Mini Mental Status Exam] and the Trail Making Test B) were associated with capacity scores. However, despite these concerns, the frequency of incapacity among older

patients with cancer does not appear to differ significantly from the general medical population of older adults.³²

Cognition may also be increasingly relevant in end-of-life care. In one illustrative study, 110 patients enrolled into hospice services without a prior diagnosis of a cognitive disorder or clinically apparent cognitive impairment underwent a 1-hour neuropsychological assessment battery and decisional capacity measures.³³ Fifty-four percent of this population was classified as having significant, previously undetected cognitive impairment. Cognitive measures of verbal abilities and global cognitive functioning were recognized to significantly predict decision-making capacity.

Other comorbidities may also influence decision-making capacity. Concomitant anxiety and/or depression can potentially contribute to altered or diminished capacity. An estimated 8–24% of patients with cancer have depression, with suspected higher prevalence in elderly adults.³⁴ Some combination of mood disorders (anxiety, depression, adjustment disorder, and dysthymia) exists in 30–40% of patients with cancer in hospital settings without a significant difference noted according to receipt of palliative care.³⁵ In severe depression, decision-making capacity may be affected, with the presumption that depressed patients tend to be less proactive in obtaining health care. A systematic review evaluating the influence of depression on medical decision-making demonstrated that patients with depression may have impaired ability to appreciate information, a core component of capacity (as described above).³⁶ There are limited data on the influence of depression on capacity in patients with cancer, but small studies suggest severe depression may potentially affect medical decision-making, suggesting a possible influence on decisional capacity. For example, in a population of patients with breast cancer and depression, only half agreed to adjuvant chemotherapy, compared to over 90% of a control group with similar disease status and treatment recommendations.³⁷ Furthermore, abnormal Geriatric Depression Screen (score >5) is also associated with capacity scores,³¹ suggesting a relationship between depression and capacity in this setting. Future research should explore the influence of psychological comorbidities such as depression on capacity and medical decision-making in oncology.

Approaching capacity in adult patients with cancer

Given the high-risk nature of many cancer therapies and the often complex decision-making scenarios in oncology, identification of individuals lacking decision-making capacity should be emphasized. Physicians struggle with determining patient competency and often overestimate patient decisional capacity.³⁸ In a cross-sectional study of patients undergoing treatment for intracranial tumors, surgeons were only able to identify approximately half of patients without capacity, as compared to a formal assessment conducted by dual-qualified physician and lawyer, indicating an oversight that could potentially be rectified with more formal cognitive assessments and/or physician training.³⁹

This discrepancy can stem from many factors, as this patient population often has family representatives to assist in providing health information that may limit the physician's opportunity to assess the patient's situational comprehension.³² In general, older adults with cancer are at high risk for suboptimal communication with health professionals. Compared

to their younger counterparts, these patients have been found to be less assertive in interviews, asking both fewer and less in-depth questions. Low health literacy can further worsen the asymmetry of this conversation, as patients with low health literacy are also less likely to ask questions for fear of “slowing down the conversation.” By this same logic, repetition of information is less likely to occur. The same obstacles may apply to older patients with hearing or memory deficits.^{40,41}

With these factors contributing to physician overestimation of capacity, effective physician-patient communication is of prime importance. A reasonable approach is to assess the patient’s decision-making capacity prior to testing, treatment, and determining need for third-party assistance, such as from CL psychiatry and/or ethics, as introduced previously. Interviewing the patient and family members separately can be a valuable first step in assessing any cognitive impairment, as language and thought disturbances may be revealed in these independent interviews. Though a full description of capacity assessment tools is outside the scope of this review, brief cognitive assessments may be helpful; even patients with milder forms of abnormal cognition may have reduced capacity. If screening evaluation for cognition is abnormal, further evaluation through referral for neuropsychological assessment and imaging may be warranted. Following identification of impaired cognition, some adjunctive treatments have been shown to help improve cognition in patients with brain metastases, including cognitive rehabilitation, exercise, biofeedback, and neurostimulants, although whether interventions affected decisional capacity was not specifically assessed in these studies.⁴²

Decision support for adult patients with cancer

Depending on the complexity of the decision at hand, patients may require assistance with health-related decision-making. In many cases, family members will assist when capacity is compromised; in the context of advanced cancer, much of this relates to treatment options and end-of-life decision-making. As these decisions often affect family caregivers, a majority of patients with advanced cancer do desire to have family members involved. This role can take many forms with family members collectively acting to make decisions or appointing a delegated decision-maker.⁴³ With increasing cognitive impairment, both patients and family caregivers accordingly prefer dominance of family decision-making. However, this can be affected by patient education, with higher education associated with preferring a patient-dominant role in treatment decisions.⁴⁴ In general, an ideal approach involves having goals of care discussions, including understanding patients’ overall goals and preferences and discussions about what treatments/interventions are tolerable to the patient, while the patient still retains capacity. Importantly, absence of (or diminished) capacity does not imply that a patient should not have a voice in decisions about their care. Though in such cases a surrogate is tasked with ultimately making medical decisions, the role of the surrogate remains still to make decisions on behalf of the patient, and the patient’s present voice—even in an incapacitated state—can and should be considered in these decisions.

Considering capacity in unique scenarios relevant to oncology

As we have described, intact capacity is integral for legally- and ethically-sound informed consent. This becomes particularly poignant when considering high-risk treatments and/or patient enrollment in clinical trials. For example, most institutions require informed consent form completion prior to initiation of cancer treatments such as chemotherapy administration, and assessing decisional capacity is particularly relevant in this regard. Additionally, clinical trials are an important means by which to advance the field of cancer care, and the decision to participate in a clinical trial is often a highly complex decision. Patients with comorbidities such as cognitive impairment are underrepresented in oncology research, and one barrier to this is likely related to their capacity to provide informed consent. However, little is known about the optimal approach for managing cancer in patients with cancer and cognitive impairment, and future research is needed in this area.³⁰ In each of these situations, however, it is important to recognize that informed consent is a process—one that takes time and often multiple in-depth conversations—and not just the signature on a form, independent of a patient’s decisional capacity

Those with cognitive impairment are often excluded in geriatric research as well. A review of a geriatric medicine journal and its inclusion criteria revealed that 29% of studies excluded patients outright for cognitive impairment based on indeterminate criteria and without clear reasons for doing so.⁴⁵ The need for greater representation is evident, and oncology clinical trials specifically designed for this population would enhance understanding about the optimal treatment approach for these patients.

Can surrogate decision-makers opt on behalf of incapacitated patients to enroll them in clinical trials, if doing so is aligned with the patients’ advance directives and wishes? In the non-oncology setting, unique scenarios exist where clinical trials bypass initial informed consent procedures in critical care and emergency room settings, with the rationale that such care is emergent and often life-saving. Numerous clinical trials are also conducted in dementia research, and prior work has demonstrated that family surrogate consent-based research in dementia is broadly supported by older Americans.⁴⁷

Also, in such cases, it is important to remember that there are several categorical capacity determinations. As introduced earlier, while some patients might lack full capacity to consent for a drug or procedure, they may still retain the capacity to appoint a proxy to make these decisions for them. In one informative trial, 37.7% of patients deemed to lack capacity to consent for a randomized drug trial were still found to have capacity to appoint a “research proxy” for that purpose.⁴⁸ In a cross-sectional review of over 100 IRBs, there was great variability in surrogate decision making for incapacitated adults enrolling in research studies in an intensive care unit (ICU) setting.⁴⁹ Six percent of these boards did not accept surrogate consent and 22% accepted only certain authorized surrogates, such as parents or spouses (essentially excluding adult children and other family members). Most IRBs cited patient safety, stating they would either not allow participation or cap risk in studies without direct benefit. However, as acute illness likely contributed to cognitive impairment in these ICU patients, policies on already incapacitated patients in research could be further clarified for early phase research trials. Another important consideration here is that legal standards

for surrogate decision-making (and who is designated as the decision maker in the absence of a designated health care proxy) vary by state. A full review of these differences is beyond this scope of this paper, but it is important to be aware of these statutes in one's place of practice. Legal and/or ethics support can be of assistance when questions about this arise in clinical care.

Medical decision-making in pediatric oncology

In care of adult patients, the relationship between the clinician and patient (or surrogate) is a dyadic one. In pediatrics, however, this relationship expands to include the clinician, pediatric patient, and surrogate decision-maker (who in most cases is the child's parent).[†] This expansion adds additional layers of complexity to pediatric medicine and pediatric medical decision-making. While the child's parent is tasked with making choices for their child, the interests of the parent and child may not always be perfectly aligned. As a result, it is important to consider the interests of the parent and child both together and independently as we consider medical decision-making in pediatric oncology. Further, in adult medicine, the surrogate typically is tasked with *substituted judgment*, making the decision that the patient would make, if they were competent to do so themselves (though this varies somewhat by jurisdiction and circumstances, with some jurisdictions and scenarios requiring reliance on the best interests standard).⁵⁰ In contrast, minors have never been competent, so making medical decisions on their behalf cannot use this guiding principle.

Unique features of pediatric decision-making

The age of legal majority is 18 years in most jurisdictions, but this varies slightly. Minor children (typically those <18 years) cannot legally make medical decisions for themselves. Instead, parents provide consent (often referenced as *permission*, to distinguish this from an adult patient providing consent for themselves) and, when appropriate, the child provides *assent* for a given treatment or intervention.⁵¹ As such, decisional capacity is not considered for children the same way it is for adults. That is not to say, however, that the preferences and choices of a toddler, for example, should be considered identically to those of an adolescent. Though both are legally minors, there are clear neurobiological and developmental differences between the way a toddler and adolescent can weigh options, conceptualize potential outcomes, etc.⁵² Most would argue that an adolescent should have a greater voice in medical decisions for themselves than would a toddler, and that this role might vary according to the complexity of the decision and level of risk associated with the choice. This graded approach is analogous to the "sliding scale" approach described earlier in reference to adults with less than full decisional capacity.¹⁵ This often unfolds in practice via the "rule of sevens,"⁵³ which provides guidance for when assent of the minor is required, based on the likelihood that he/she has capacity (TABLE 2). Notably, however, this "rule" is not based in law; rather, it is meant to serve as a guide regarding how optimally to include children in decisions about their medical care.

[†]While the designated surrogate for a child varies (e.g., biological parent, foster parent, grandparent, etc.), the surrogate most commonly is the child's parent(s). As a result, for sake of simplicity, we will refer to the child's parent to mean their duly appointed surrogate decision-maker.

Importantly, minors are considered to be a vulnerable population, both legally and ethically. As such, various protections are put in place regarding medical decisions made on behalf of children that do not exist (or exist to a lesser degree) regarding decisions made by a surrogate for an incapacitated adult. Parents generally are given significant discretion with regard to the decisions they make about their children's medical care. Parental authority is not without limits, however, due to society's interest in the wellbeing of children (the doctrine of *parens patriae*).⁵² As a result, various frameworks exist regarding when to override parents' refusals of recommended medical treatments^{54–56} and/or requests for non-recommended treatments.⁵⁷ Such disagreements between parents and clinicians are relatively rare, but when they take place, they can be quite contentious and controversial.

Adolescent decision-making

Adolescence (typically defined as the period between 12 and 18 years, though sometimes classified as starting as early as 10) is a particularly unique period in pediatric decision-making. According to the aforementioned rule of sevens, adolescents should always provide assent for medical treatments given that they are presumed to have decisional capacity unless proven otherwise. However, many adolescents make risky choices and succumb readily to peer pressure, and we know that the prefrontal cortex—the area that oversees such functions as weighing risks and benefits—does not fully mature until well into the third decade of life.⁵⁸ So should adolescents be permitted to make potentially irreversibly life-altering decisions about their medical care, particularly if such decisions are likely to be life-limiting? If so, how should this be done, given that their parents ultimately have legal decision-making authority? This is an area of great controversy, but one that occasionally plays out on the front pages (see, for example the cases of Billy Best, Abraham Cheerix, and Cassandra Callender, teenagers whose refusals of treatment for highly curable Hodgkin lymphoma made national news).^{59–61} Many argue that adolescents should not be allowed to refuse life-saving treatments, but it remains unclear how best to navigate such challenging scenarios. Recent work has demonstrated that adolescents with cancer most often wish to share decision-making responsibilities regarding their cancer with their parents and oncologist, but they hold their preferred decision-making role in only 2/3 of cases.⁶² A recent systematic review identified that children and adolescents with cancer who expressed that their oncologist addressed their informational and developmental needs experienced a sense of control, safety, and agency, particularly when compared to those whose needs were not met.⁶³ Certainly, the optimal case is that in which the pediatric patient, their parent, and the clinical team are in agreement with regard to their cancer care,⁵⁰ but how best to achieve that goal in caring for a child with cancer remains elusive.

Cross-disciplinary lessons

Are there lessons regarding decisional capacity that can be learned from pediatric oncology and applied to medical oncology, and vice versa? A core feature of pediatric care has long entailed including the child's voice in their care when possible, even though they typically do not make the final decisions regarding their care. A similar model can be used in care for incapacitated adults with cancer, with their values/perspectives integrated into medical decisions, even when decisional authority ultimately lies with their surrogate. Likewise,

numerous instruments for capacity assessment exist for adults, though these vary in their reliability and precision.¹³ Presently, pediatric decision-making takes into account age and developmental status when considering the role of a child/adolescent in their medical decisions, but few pediatric assessment instruments exist.⁶⁴ This remains true even when considering whether an adolescent should be deemed a “mature minor,” whereby some minors can be granted decisional authority.⁵⁰ This area would likely benefit from the rigor and care taken in developing, testing, and utilizing such instruments in adults. These are but a sampling of the many areas in which pediatric and medical oncology clinicians and researchers can work together to improve care for patients with cancer across the age spectrum.

Conclusions

Modern medical practice emphasizes the importance of the right to self-determination regarding medical interventions. However, questions often arise whether a given patient has full decisional capacity, potentially comprising their ability to make these decisions for themselves. This is an important consideration in general medicine, but perhaps even more so in oncology, wherein capacity can be affected by underlying disease (primary disease or CNS metastases), treatment effects, and/or comorbidities unrelated to the underlying cancer diagnosis. Further, in pediatric oncology, minor children are assumed not to have capacity but generally take on a successively greater role in their medical decisions as they grow and develop.

While these fundamental principles are rather straight-forward, putting these into practice in oncology proves far more complex. Assessing patient capacity is an inexact science, but it is an essential component of care for patients with cancer. Further, limited data exist on how cancer, cancer-directed therapies, and underlying comorbidities together impact capacity, particularly over time and with changing clinical circumstances. Finally, how best to integrate the choices/perspectives of minor children into their cancer care remains ill-defined, particularly when those choices conflict with those of their parents and/or oncologists. Researchers continue to examine these many complexities, shedding light on not only the role of capacity in oncology care but also how we can better assess capacity and care for those who lack capacity. As the field of oncology progresses via precision medicine, immunotherapy, and many other exciting advances, understanding the role of decisional capacity in care of patients with cancer of all ages will become only more important.

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PRACTICAL APPLICATION BULLETS

- Patients with cancer must have decisional capacity to have the legal and ethical authority to make decisions about their medical care.
- Decisional capacity in patients with cancer can be impacted by numerous factors including their underlying disease (primary disease or CNS metastases), treatment effects, and/or comorbidities unrelated to the underlying cancer diagnosis.
- Some patients with cancer (such as children under the age of 18 years) do not yet have authority to make their own independent medical decisions.
- Numerous tools and guidelines exist to support oncology clinicians in assessing patients' capacity and understanding how best to care for patients with cancer who do not have full capacity.

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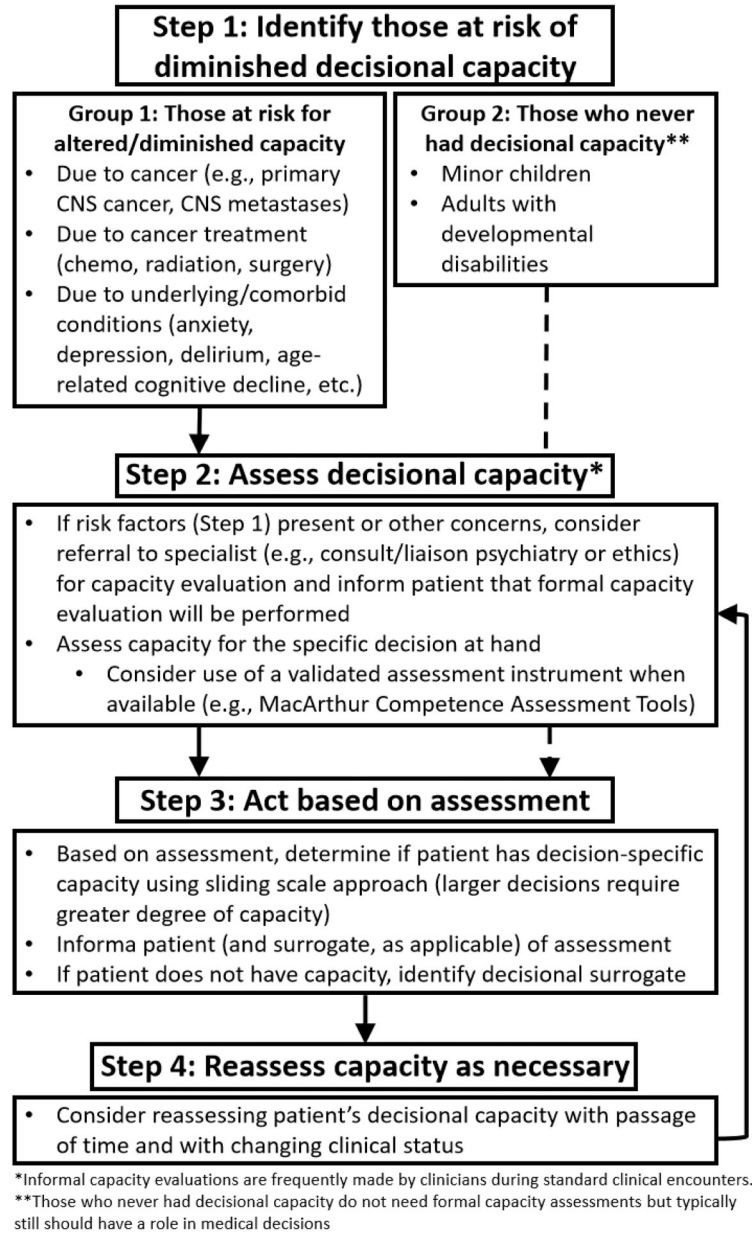


FIGURE 1: Model decisional capacity assessment framework for patients with cancer

TABLE 1:

Ethically required elements of decisional capacity

Decisional element	Definition	Case example
Understanding	The patient's ability to grasp the meaning of information communicated by the physician and other caregivers.*	Mr. Smith has just been diagnosed with advanced colon cancer, but he has been completely silent while his physician explains to him the diagnosis and recommended treatment. Further inquiry is necessary to ensure that he understands the information that has been communicated to him.
Appreciation	The patient's ability to appreciate the consequences of their situation (medical condition, need for treatment [when applicable], and likely benefits and harms of each possible treatment)	Mr. Smith is a highly educated patient who has clearly understood the information conveyed, but he seems to question how certain it is that he really has cancer and thus whether any treatment is actually needed. Exploration of his appreciation of his condition is clearly needed.
Reasoning	Patient can weigh risks and benefits within/ across treatment options and arrive at a decision that is consistent with their starting premise(s)	Mr. Smith has been clear that he places great value on comfort but elects a treatment approach that is likely to cause substantial distress. This discordance deserves a careful inquiry into the reasoning underlying that decision.
Communicating a choice	Patient can clearly indicate their preferred treatment option and maintain that choice for a sufficient period of time for it to be implemented	Mr. Smith demonstrates great ambivalence about a treatment choice, not clearly embracing any option but shifting among them. The basis for that ambivalence should be explored and, if possible, resolved.

* Generally, relevant information that must be understood is encompassed by the requirements of informed consent (the nature of the patient's condition, the nature and purpose of the proposed treatment, risk and benefits of the proposed treatment, and reasonable alternatives with their respective risks and benefits).⁸

TABLE 2:The Rule of Sevens⁵³

Age range	Role for assent	Rationale
0 to 7 years	No assent required	Little to no possibility of decisional capacity
7 to 14 years	Assent not required, but child should be informed of medical plans	Lack of decisional capacity is assumed in absence of evidence demonstrating otherwise
14 to 21 years*	Assent required	Decisional capacity is assumed in absence of evidence demonstrating otherwise, although patients under 18 generally lack legal authority to make decisions on their own.

* Notably, in most of the United States, the legal age of majority is 18 years, so assent does not apply for those 18 years