

Rethinking autonomy: decision making between patient and surgeon in advanced illnesses

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Abstract: Patients with advanced illness such as advanced stage cancer presenting with the need for possible surgical intervention can be some of the most challenging cases for a surgeon. Often there are multiple factors influencing the decisions made. For patients they are facing not just the effects of the disease on their body, but the stark realization that the disease will also limit their life. Not only are these factors a consideration when patients are making decisions, but also the desire to make the decision that is best for themselves, the autonomous decision. Also included in this process for the patient facing the possible need for an intervention is the surgeon. While patient autonomy remains one of the main principles within medicine, guiding treatment decisions, there is also the surgeon's autonomy to be considered. Surgeons determine if there is even a possible intervention to be offered to patients, a decision making process that respects surgeons' autonomous choices and includes elements of paternalism as surgeons utilize their expertise to make decisions. Included in the treatment decisions that are made and the care of the patient is the impact patients' outcomes have on the surgeon, the inherent drive to be the best for the patient and desire for good outcomes for the patient. While both the patient's and surgeon's autonomy are a dynamic interface influencing decision making, the main goal for the patient facing a palliative procedure is that of making treatment decisions based on the concept of shared decision making, always giving primary consideration to the patient's goals and values. Lastly, regardless of the decision made, it is the responsibility of surgeons to their patients to be a source of support through this challenging time.

Keywords: Advanced illness; autonomy; palliative care; shared decision making; surgery

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Mr. Jones presents to a surgeon's office for a second opinion regarding his colon cancer. He has advanced disease with metastases to his liver and lungs complicated by multiple other medical co-morbidities. Prior to this consultation, he has been seen by other physicians, both surgeons and medical oncologists. Previously, surgeons have declined to operate while the oncologists offered him palliative chemotherapy. Consistent with the recommendations of the other consultants, the surgeon does not offer operative treatment for his advanced cancer at this time. Mr. Jones

presents to the hospital 1 month later with what appears to be a malignant bowel obstruction.

Patients like Mr. Jones present a challenging clinical dilemma for surgeons; how can they best use their skills and knowledge to address the needs of patients with advanced illnesses? There are many dynamic factors at play that can influence the decision making for patients and their physicians. In medical decision making the ethical principle of autonomy, or right of self-determination must be respected. Physicians must adequately inform

their patients to ensure that they can make autonomous decisions. While the goal is always to respect patient autonomy, surgeon autonomy must be considered as well. Consistent with the ethical principles of beneficence and non-maleficence, surgeons are responsible for determining possible interventions to offer their patients that might be beneficial and not harmful. However, only patients' values and goals in collision with the reality of a limited prognosis can provide a meaningful context for understanding what is truly beneficial and not harmful. Whether terminally ill patients' goals of care are primarily focused on enjoying their remaining time with relief of any distressing symptoms or the continued pursuit of life-prolonging treatment, determination of a course of action will depend upon a shared decision making process that respects both patient and surgeon autonomy.

Introduction

The patient-physician relationship is undoubtedly distinct and unlike almost any other relationship between persons. For the physician there is a desire to help patients, whereas for the patient entering into this relationship there is a need for the physician's services. An important foundation of this relationship is the principle of implicit trust; trust that the physician will do what is best for the patient. Unfortunately, patients are often confronted with limited options regarding their choice of physicians due to the requirements of health insurers and the nature of acute inpatient care. Even then the primary physician responsible for a patient's overall care can be constantly changing. Ideally, patients can develop meaningful, ongoing relationships with their physicians, but urgent or emergent situations may limit such opportunities.

The patient-surgeon relationship poses some unique challenges for both patients and surgeons. For surgeons, there is a unique tension between the goals of beneficence and non-maleficence; the invasive interventions they offer their patients, while intended to help, can also bring significant harm. Patients place their trust and confidence in surgeons with the assumption that their interventions are always meant to and expected to help. When determining treatment plans and care options for surgical patients, additional factors influence the final decision and plan. Those factors include, but are not limited to, what resources does the hospital have, what skills does the surgeon have, the patient's anatomy, the patient's overall status and what are the surgical options for the patient. Over the years medical decision making has been transformed from a

paternalistic view in which the physician made decisions for the patient to that of patient autonomy and the right to decide as the standard. While the patient's right to decide is of utmost importance it still remains the responsibility of the physician to ensure patients have been provided the knowledge they need, to elicit their preferences and collaborate with the patient in the decision making process in what has become known as shared decision making.

Among the many challenges and complexities that are an inherent part of the practice of medicine, caring for the patient who is in the late stages of an advanced illness can be particularly challenging. It can be a stressful time for all involved, patient, family and physician, with personal values and goals at stake and no perfect algorithm to follow. It can become a medical and moral dilemma, especially for patients who may benefit from operative interventions, but pose an inordinate operative risk or for those patients who greatly desire an operation even when it will likely not provide any meaningful benefit. An ethical tug of war may ensue between patients' and surgeons' goals and desires, always keeping in mind the oath to do no harm. In such difficult situations, how can patient and surgeon autonomy be balanced with the ultimate goal of helping the patient while avoiding harm?

The patient

Autonomy, beneficence, non-maleficence and justice, the four main principles of bioethics, are often utilized to shape our decision making within the medical field. While one does not take precedence over another, the concept of autonomy or self-rule has become the basis of patient decision making. Respecting autonomy allows patients to make decisions that are in their best interests, as they are usually the best judges of those interests (1). In past years much of the decisions made in medicine were made by physicians determining what they felt was best for the patient. Since then there has been a transition from medical paternalism to an increasing recognition of patient autonomy or the patient's right to decide (2,3). Although this shift in authority has clearly occurred between physician and patient decision making, there still remains the responsibility of the physician to the patient. While the physician is not making the decisions for the patient, the physician has a depth of knowledge the patient will not have and thus, it is incumbent upon the physician to guide the patient through this process (1,4,5). With the specialized medical knowledge and relationship of trust that

ideally is formed between surgeons and their patients, it is the responsibility of surgeons to sufficiently inform their patients so that they can make decisions based on their goals and values. When they are not adequately informed, patients will be unable to balance the benefits and harms and how each will affect their goals and quality of life; in a sense this is not respecting patient autonomy (6). For each individual it is important to remember that decisions will be individualized; the decisions made will be based on the weight given to different elements of the decision and how the likely outcomes will in turn interact with and affect the values of the individual (1,4).

For our patient Mr. Jones, while the standard of care for someone in his situation is in line with the surgeon's initial recommendation for no operative intervention (as determined at the clinic visit), the surgeon is still responsible for ensuring that the patient is provided the information and reasoning as to why the decision was made. For patients who are not experts in their disease, what they are most often left with are trust. It is trust that the surgeon will provide them with the information and explanation they need to make decisions or why a decision was made (1,7). This can be challenging as each patient may require different levels or kinds of information and knowledge. In an ideal situation there will be adequate time to truly get to know patients and determine what knowledge should be shared with them based on their values, but unfortunately this often does not occur (3,8). What physicians are left with is trying to provide the information that a "reasonable" person would want to know (3). Thus, providing information to a patient may not be based on what the patient needs, but on what a physician feels is what most everyone else in the same situation would want to know. While this has become the standard in bioethics, the physician must keep in mind that each patient is different, with varying needs which must be respected in order to honor the patient's autonomy.

While the previous recommendation for no operative intervention is considered standard of care, Mr. Jones has now presented to the hospital with a new diagnosis. As all of the facts are not known, it is safe to assume there is a reconsideration of possible interventions to address and treat this new complication of his disease process, malignant bowel obstruction. Mr. Jones is likely facing treatment of his obstruction by conservative (medical) management or operative intervention. As he is facing this possible decision, it will be imperative for the physician to provide him with the adequate information he will need,

as discussed above. In order for surgeons to fully respect their patients' autonomous decision the information provided should be pertinent to the issues and of sufficient detail so that patients can determine how it correlates with their values and goals. The subsequent process of shared decision making that follows the delivery of this information is essential to respecting the patient's right to decide. Within this process it is not just a statement of facts with the patient left to decide, but a dialogue among all involved. This dialogue must involve an understanding of the disease, what are the possible treatment options, and the risks and benefits involved. While the patient listens to the surgeon's thoughts, it is crucial for surgeons to elicit and listen to their patient's values and goals before true shared decision making can occur. After this has occurred, patients can make informed decisions in collaboration with their surgeons. In the context of advanced illness, when considering a potentially dangerous procedure that may be of limited benefit, it is important to realize that shared decision making is not a static event, but an evolving process. Ideally, shared decision making can create the opportunity for patients to explore all of their concerns and questions, eventually leading to the choice that is best for them, even when faced with limited options. When the options are limited to choices the patient would prefer not to make, it may be essential that the process extend beyond a single discussion between surgeon and patient. Facing the gut wrenching possibility of less than ideal or even no treatment options other than comfort care can be a very bitter pill to swallow for some patients facing their death. Allowing patients to fully participate with the surgeon in reviewing their options in relation to achievable goals can help honor their autonomy and restore a sense of control.

For the patient faced with progressive disease, nearing the end-of-life, there are often many changes occurring, emotions felt and evolution of relationships. While Mr. Jones is facing the prospect of a difficult decision, other patients often face the choice of no other "treatment" options from their physicians. During this time as patients contemplate the prospect of their impending death, they may also be sensing or even grieving a loss of the relationship they have with their physician (9). With the loss of this relationship, patients may also fear they are losing their physician's medical expertise (9). Physicians at the same time may harbor concerns that during this time of transitions in care patients will feel a sense of abandonment. Situations such as these highlight patients' fears of being abandoned by their physicians not just at the end-of-life,

but in other times of need as well (10). Regardless of the initial reason for its foundation, once patient-physician relationships have developed, there must be an ongoing commitment to care for patients within these partnerships, which continues as shared decision making between patients and physicians throughout the course of the illness to the greatest extent possible (10). While non-abandonment is viewed as an ethical and even legal obligation of a physician, it is also a core value of the medical profession that is reflected in the commitment to care for all patients (10). Patients are ensured the care of their physician and the physician's commitment throughout the course of their entire illness, regardless of the outcome.

For patients facing the prospect of a palliative procedure at or near the end-of-life, these concepts of autonomy shared decision making and non-abandonment become even more important. With the prospect of limited time, every decision becomes important as the patient focuses on what will help them achieve their goals. Likewise, for their surgeons the limited time remaining in which to honor their terminally ill patients' autonomy while faithfully accompanying them to the end of their journey poses a direct challenge to surgeons' commitment to non-abandonment in the context of an emotionally charged and taxing relationship. Death can often be a difficult topic to discuss, with many often shying away from or completely ignoring the subject. While it may be uncomfortable to discuss future care plans regarding advanced illness or even death it leaves a gap in the patient-physician relationship. Patients have reported a lack of communication regarding eliciting their preferences, outcomes of their disease and advanced care planning for many years (11). While the final decision regarding one's care plans ultimately should be the patient's decision, it has been shown they do value the input of the physician (12,13). As uncomfortable and uneasy as the conversation may be it becomes the duty of the physician to explore these topics with the patient. Misalignment in this understanding can lead to unrealistic expectations and even excess or unwanted treatment (14,15). This process of eliciting the patient's wishes will always remain in flux; as conditions change and treatment decisions evolve there will always be a need for continued communication and reassessment of patients' understanding and wishes (16,17). The importance of this communication is ensuring the best decisions are made to honor the patient's goals and values, and for the physician to remain a source of empathy and support for the patient even when they have no curative treatment options to offer (16-18).

The surgeon

Surgeons, like other physicians and health professionals, have an inherent desire to heal patients, which may often be colored with an unwavering dedication to curing the disease. While surgeons may often be accused of living by the mantra to cut is to heal, those entering the surgical specialties initially focus their attention on learning how to operate, but spend the rest of their careers learning the more subtle art of when not to operate. In many cases, especially those in which palliation is the primary intent, as is the case for Mr. Jones and treatment of his bowel obstruction, a fine line must be traveled in deciding whether an operation will help or cause more harm to the patient. For surgeons these are the most challenging cases, both physically and mentally. Often the patient's disease process is such that the operation will not be quick, easy, or with minimal blood loss and without complications. Frequently, in advanced illnesses like cancer, patients' bodies have been ravaged by their disease, taking even the simplest of operations to a more challenging level. Also impacting the physician is the amount of mental fortitude involved in the decision making for these patients. The desire to help patients has to be balanced with the intention not to maim the patient; how to help without adding undue harm. Unfortunately, the decision to operate on such patients is not straight forward and there are no established algorithms or guidelines. The decision rests in the relationship formed between the patient and surgeon; while the patient has the final authority to say yes or no to a proposed course of action, what role does the surgeon's right to choose play in this situation? What about the surgeon's autonomy?

The patient-surgeon relationship is a unique relationship in medicine. It must be one that is entered into with mutual acceptance and understanding of both the nature and risks of surgical intervention from both parties; otherwise the physical impact of surgeons on their patients could be considered a form of assault. By performing operations, surgeons gain an intimate view of their patients that no others have, which can create a bond that can only be appreciated fully by those individuals (19). In order to create and sustain the patients of this relationship must trust that their surgeons will uphold the principles of beneficence and non-maleficence during their care and treatment. It is this unique relationship that is the foundation to many decisions the surgeon makes; always weighing what realistically can and cannot be done to help the patient.

Insight into the surgeon's mind was first presented by

Charles Bosk in *Forgive and Remember: managing medical failure* (20). Since that initial study there have been other studies that have tried to understand the surgeon's perspective and how decisions to operate and not to operate are made. By offering an operation, surgeons are not only agreeing to perform the best operation they can, they have also acknowledged an intense personal responsibility to their patients (21). It is this responsibility to patients before, during and after operations that often shapes the actions of surgeons. Work done by Schwarze and colleagues, which evaluated surgeons' conversations with patients regarding high risk operations and life support offers insight into the minds of surgeons and what they inherently feel is their responsibility to their patients (22). When entering into the patient-surgeon relationship there is an agreement by both sides, that each will commit to getting through the operation and any issues that may arise in the postoperative period (22). After this mutual understanding is forged, surgeons often retain a strong sense of responsibility, which may make any future deviation from the original plan challenging. Any subsequent complications follow up visits, readmissions, or need for further interventions are addressed by the surgeon who entered into the initial agreement with the patient. Often surgeons feel they intimately know their patients. After all, their hands have altered the patient's anatomy and this act forms the basis for the deep sense of responsibility the surgeon feels to the patient. Surgeons only ask for another surgeon to share in this responsibility when assistance is needed or the care the patient needs is outside of their expertise.

The patient will always retain the central role in the patient-surgeon relationship but it is also important to consider the impact of this unique relationship on the surgeon. For most surgeons there is a strong drive to do better, not only for their patients but also, to improve the care they deliver to current and future patients. This dynamic of the surgeon always wanting to do better within the surgeon-patient relationship may contribute to the common perception of surgeons as "never giving up" (even if a patient may want to stop certain therapies), fighting for the patient to the end. In a survey of vascular, cardiothoracic and neurosurgeons regarding withdrawal of postoperative life support, surgeons were less likely to withdraw the support if the complication was due to surgeon error or in the context of elective (as compared to emergent) cases (23). These results offer further insight into surgeons' thought processes, but also into their own consciousness of any mistakes they have made. By prolonging life-sustaining

therapies in the face of apparent futility they may be attempting to prove to themselves and the patient that they can fix their mistakes and make their patients better. Caring for patients upon whom one has operated, is a way of life with an emotional impact that one cannot just turn on and off or disregard.

While on the way to meet Mr. Jones to discuss his malignant bowel obstruction, the surgeon will likely be pondering many different issues and decisions. One of the first decisions to be made is whether to operate or not. While in some cases the decision is straight forward, in others it may not be so simple. Most often, the especially difficult and challenging decisions are encountered in high risk procedures or those with palliative intent. Mr. Jones is not only in poor health, but with his diagnosis of malignant bowel obstruction his median survival is dismal, making the decision making process in his situation extremely challenging. While patient autonomy is the standard for decision making, there remain elements of physician autonomy that are essential to determining viable treatment options. When deciding whether to operate and which procedure to offer, surgeons must determine what they believe are the best options for their patients and make this determination by careful calculation of the trade-offs involved (24).

Another major factor impacting the surgeon's deliberations is the surgeon's perception of patient expectations. Even if the patient's expectations have been unrealistic from the beginning of their relationship, they will weigh heavily upon the surgeon at an emotional level. Now, when evaluating him again, the surgeon may be painfully aware that Mr. Jones may still be hoping that a cure is somehow possible, or at least that the surgeon can "fix" his obstruction. Patient denial can cause persistent differences in understanding between patient and surgeon of the true nature, goals, and limitations of a proposed operation in the context of terminal illness. Emotions run high in such situations and rational discourse may be severely compromised, thus threatening true autonomous decision making both on the part of patient and surgeon. The surgeon's own rational autonomous decision making will be in tension with the powerful emotions elicited by the patient's desperate plea to do something, even though that 'something' may not be appropriate, purely on rational grounds. Thus, a surgeon's sense of self-determination or autonomy can be challenged at its core as compassion fuels the desire to help the patient in spite of the rational probability of not being able to achieve the desired

outcome. As the relationship between patient and surgeon grows and the goals and values of the patient are further explored, rational discussion and reasoned autonomous decision making by both parties can become more difficult as a result of the emotional bonds that are formed. For the patient and surgeon facing a high stakes decision, emotions can trump reason and threaten the autonomous decision-making of both sides, leading to decisions that may not truly honor the patient's wishes or be consistent with the surgeon's better judgment. Surgeons may sometimes find themselves offering futile or inappropriate surgical interventions to avoid abandoning their patients even when their own clinical judgment and autonomy argue strongly against it.

In navigating these challenging situations it is not only essential to recognize the strong emotional factors affecting surgeon decision making, but also it is often a lack of competency and training in caring for and communicating with patients in palliative and end-of-life situations; which further exacerbates the problem (25,26). Surgeons are first and foremost physicians who can operate. The challenge for the surgeon is to know when not to operate but still provide appropriate medical care for a very ill patient. Not understanding this fundamental principle can lead to suboptimal care at times, provided in the form of overtreatment or treatment that is not in line with patients' values and will result in considerable frustration on the part of the surgeon. A concern as to why this occurs is the physician's fear of taking away hope from their patients by discussing these topics (16,27,28). Even though Mr. Jones presents with an urgent medical issue there is most likely still some time for his surgeon to explore what Mr. Jones is hoping for as he reaches the end of his life. Within these conversations there will be time to allow the high emotions and denial to dissipate, for the surgeon to get to know Mr. Jones as a person and for the surgeon to help guide Mr. Jones through this challenging time drawing on the surgeon's knowledge and past experiences. Even though it may be quite uncomfortable to discuss a poor prognosis or end-of-life issues, the physician must remember there is a duty to provide patients with the truth regarding their disease and that doing so can actually help the patient to be more hopeful (27,28). As the dialogue with Mr. Jones continues, he relays that he would really like to have his obstruction "fixed." He finds joy in spending time with his family, but the nausea and pain has been detrimental to those important interactions. This knowledge can help focus additional discussions of treatment options that can

help Mr. Jones achieve his goals possibly without operative intervention; thus, allowing for a shared decision to be made that honors both the patient's and surgeon's autonomy.

The patient and the surgeon

For the patient contemplating a procedure that is palliative in nature there are very few times when the decision to proceed with treatment is straight forward. Many factors are often at play and the decision is rarely made by one person. For Mr. Jones he would like improvement in his symptoms and may also still be hoping for a cure, but it must also be considered what is possible for Mr. Jones. Patients with incurable disease who have painful and distressing symptoms are a clinical dilemma. For physicians there is an inherent and powerful desire to relieve suffering and make their patients better. While data has shown the possibility of successfully relieving a patient's malignant bowel obstruction it is often accompanied by significant morbidity, mortality and even failure (29). With limited data and experience available in treating patients with the goal of palliation and having no clear algorithm the surgeon is left to determine the treatment plan based on the benefits and burdens. Unfortunately, how to determine those relative benefits and burdens prior to having an informed conversation with the patient remains largely unknown and a challenge in this patient population. In this process the definition of success must be determined. Is it to be pain free, is it to eat one's favorite meal again, and is it to live to the family reunion a few weeks away? In further defining what is success can help to determine what is possible and what is a burden to the patient. Ultimately, patients' values and goals placed within a realistic understanding of their prognosis must define success.

While one's path can never truly be predicted, the idea of prognostication has been utilized to help inform those conversations of what is to be expected and possibly help to define success. The concept of prognostication is based on many elements including patient factors, available treatments, prior experience and known data regarding a disease process. With so many data points' prognostication remains a difficult process and is often not accurate, as the estimate is always in flux depending on the clinical situation. Physicians often are poor prognosticators; an accurate estimate only occurs a fraction of the time and quite often is an overly optimistic guess (30,31). Prognostication does improve with experience, but interestingly when a physician has a stronger relationship with the patient this

is associated with a lower accuracy (30). Whether this has to do with maintaining hope, one's personal bond with the patient, or clinical factors it is unclear, but what is clear is that while in respecting patients' autonomy and informing them physicians are still limited by the boundaries of being humans and not knowing all the answers. Even with dramatic advancement of medical technologies and the continuous improvement of health care, determining patient outcomes remains an imprecise science at best. Often enough, patients undergoing palliative procedures meet their surgeon when the situation is urgent or even emergent, which leaves little time for the two to form an in-depth relationship, in which to explore the patients' goals and values in order to fully address their questions and concerns (8). Because of this there have been many scoring systems created based on clinical and patient factors to help provide possible prognostic information to the patient, to guide the decision making process, when faced with limited time to make decisions (32-34). While determining these factors are helpful to physicians to supplement their decision making process and discussions with patients there is an unfortunate fact that these models can have variable accuracy and at times are not helpful (35,36). The surgeon must keep in mind that while these prediction models can help to add clinical information and even an idea regarding possible outcomes, they are not a substitute for talking with the patient and determining what their goals are so that a plan can be developed to possibly achieve those goals and improve symptoms for the palliative patient.

While the scoring systems that have been established to determine a patient's prognosis or prediction of outcomes remain imprecise there are ways to determine a general prognosis. For patients with advanced illness, especially cancer, there are a few main factors that can be utilized to estimate a prognosis. These include (I) the stage and relative aggressiveness of the disease; (II) the risk of any emergent complications of the disease; and (III) the patient's functional status. Scoring systems such as the Eastern Cooperative Oncology Group (ECOG), the Palliative Performance Scale and Karnofsky Performance Status that determine a patient's functional status have been demonstrated to correspond with survival estimate for their disease (37,38). These scores in consideration with disease factors and risk of complications from the disease can give the patient and the physician an estimate of their prognosis. Patients with advanced, incurable and progressive illnesses (e.g., metastatic cancer) without any immediately life-threatening complications but who can perform all their

basic Activities of Daily Livings (ADLs) and some complex or instrumental ADLs (e.g., domestic chores, shopping) likely have months to live (ECOG 1-2); those with incurable, advanced disease who are needing to rest up to half of the day time and need some assistance with basic ADLs (e.g., bathing) likely have weeks to a few months at best (ECOG 3); those with advanced, incurable disease who are now essentially bedfast have days to a few weeks at best. As well, poor pain and symptom control can contribute significantly to what appears to be a worse prognosis.

While the various prediction models may be helpful in adding to the conversation, at a more fundamental level there is another factor that guides the decision making for many if not most patients and that is the implicit trust patients have in their surgeon. Surgeons have an inherent knowledge base due to their training and past experiences that help them to make clinical decisions in patient care. And while it is the responsibility of surgeons to use this knowledge to provide their patients with the facts they need to make informed decisions regarding their care, there is also an element of patient entrustment in the surgeon to guide them in the "right" direction. During these difficult times patients may not only lack knowledge and understanding regarding their disease, but are in a state of disbelief and distress that creates further challenges to the decision making process. Previous studies in esophageal and pancreatic cancer patients have shed more light into this concept of patients placing trust in their surgeon (39,40). There is the idea that surgery is the way to a cure, which is often based on patients' prior experiences or the experiences of others who have undergone an operation. These perceptions may be further affected by prior experiences with loved ones or friends whose disease was too far advanced for an operation, raising the lingering question of a different outcome, if an operation could have been performed. There is also the thought that if one is being referred to a surgeon, there are good reasons this referral occurred at this time and to that specific surgeon. Thus, patients place trust in what many may view as the surgeon's skill and expertise to provide 'curative' therapy and tend to accept any treatment they may recommend. And finally for many patients, trusting surgeons and their recommendations also means being resigned to the risks involved. The risks would have to be accepted, whatever they may be, in order to undergo the operation, especially when it is viewed as their only option (39-41). This concept of feeling that there are no other options other than what the physician or surgeon is recommending has been

observed in other disease processes and treatment plans that involve a high risk to benefit ratio. In children undergoing bone marrow transplants, often parents have felt there was no decision to be made, it was either undergo the treatment or die (42). Physicians and especially surgeons must realize and be cognizant that often patients are placing their trust and essentially their lives in the hands of the medical profession with the expectation that their physicians will provide them with recommendations that have their best interests in mind.

There will always be an internal struggle for the surgeon caring for the palliative patient when attempting to weigh the many forces that go into deciding to offer an operative intervention. One must first make the decision of what realistically can be offered to the patient under the circumstances. If the surgeon does decide to offer an intervention, one must keep in mind truth telling and providing patients with the information they need to make an informed decision, while also realizing patients will often place a significant amount of trust in the surgeons' recommendations. While patient autonomy is of the utmost importance, in reality the surgeon, must retain some level of paternalism, using the best interest standard, when the patient, through an act of trust, relinquishes further decision making to the surgeon during the actual operation. It becomes the surgeon's duty to balance the desire to help the patient yet to prevent harm when treating and caring for the palliative patient. The ethical challenge for surgeons is to continue to honor their patients' autonomy during the postoperative period by restoring as much shared decision making as possible.

Palliative procedures compose up to 20% of a surgical oncologist's case load (26,43,44). While many definitions may exist to define a palliative procedure; in general, palliative procedures are those viewed as being performed with the primary intention of improving or relieving a patient's symptoms (pain, bleeding, nausea, obstruction, etc.) without the direct intention to cure or prolong life (26,45). When discussing a palliative procedure with a patient this distinction regarding the primary goal of symptom improvement and not cure must be emphasized. The surgeon must keep in mind that while a procedure is being performed for palliative intent with the above definition in mind, there can be many potential outcomes (and unfortunately complications) for which the patient should be informed of, when making treatment decisions. For some patients undergoing an operative procedure there is a chance of achieving the best ultimate outcome,

not only symptom relief, but also cure of the disease causing the symptoms. While this is the best outcome that one can achieve, most often for this patient population it is a rare situation, such as the patient presenting with advanced cancer and acute cholecystitis undergoing a cholecystectomy, relieving them of the disease (cholecystitis) and the associated symptoms. Another situation that can be viewed in many ways from the standard definition of a clinical success (cure) to that of utter failure is for patients who may have been cured, but in the process, the procedure did not help or even made their symptoms worse. For some, the symptoms and the distress they cause can be worse than the security of having a cure. A third outcome of undergoing a procedure is that of not achieving cure, but improving the patient's symptoms and, in turn, their quality of life. This is the definition of a truly palliative procedure. Lastly, the surgeon must realize there is one other possible outcome, one in which no improvement is made in the patient's symptoms; as well, the symptoms and poor quality of life of the patient may have been exacerbated by the procedure. While it is impossible to determine for each patient what outcome they may have, the surgeon must be prepared to discuss these possibilities with the patient and care for them after the operation.

With these many possibilities in mind, one can be left wondering what the definition of a good outcome for these patients might be. As noted above, the practice of medicine is fraught with uncertainty leading to deficiencies in prognostication so that no prediction model is perfect. At the same time when trying to relay our predictions to patients there is a lack of meaningful outcomes data to help shape this decision making process, in no small part due to the great difficulty inherent to performing clinical research with patients at the end of life. If the definition of a palliative procedure is based on symptom improvement and not cure or even necessarily prolonging a patient's life, then outcome measures other than mortality are needed. But the stark reality is that mortality and morbidity are the outcomes that are recognized for all physicians and hospitals. It is these values that are reported when grading and ranking hospitals and individual physicians (46). Due to this fact, morbidity and mortality are often what is reported in patients undergoing a palliative procedure (47). While understanding the likely morbidity and mortality of a procedure are important issues to discuss with a patient, there is still a lack of information on the success of achieving patients' goals, including symptom improvement. There needs to be more reporting and studies structured such that

the outcomes measured include symptom improvement and quality of life scores. With this approach patients and their surgeons, together can utilize more pertinent data to help them determine if the procedure being contemplated will aid them in achieving their mutually constructed goals. With this there also would need to be a rethinking of publically reported outcomes for this patient population, with different goals for a palliative intervention come different success measures (48).

Lastly, it is important to consider the patient for whom operative intervention may cause more harm than good. While surgeons strive to achieve the very best outcomes for their patients there are times, unfortunately, when failure occurs. For patients contemplating a palliative procedure it is a time of unknowns, difficult decisions and a realization of their own possible mortality. It can also be a time of loneliness, fear and loss of control. And as seen in many studies, patients are better able to face these challenges by the level of trust they place in their surgeons, confident that they will make the right decision and have their best interests in mind (22,39,40,42). For surgeons whose first impulse may be to offer an operation, their greatest professional challenge may be to acknowledge both to themselves and to their suffering patients when it is not appropriate or in their patients' best interests to offer a procedure. No surgeon or any other physician ever intends to add to a patient's suffering or recommend a therapy or procedure that in error hastens a patient's death. At times the best treatment may not be an operative intervention, but being a support to the patient, someone they can rely on during the course of their illness (19,23,25,49,50). Even though surgeons may feel unprepared for dealing with the unique needs of patients at the end-of-life, patients want their surgeons to be present for them during this time (19,25,51,52). Stepping back from the familiar role of surgeon, the sworn enemy of death, to that of being a physician and fellow human being who witnesses and supports one's patients as they encounter the inevitable 'facts of life' is extremely difficult, but has rewards that can only be discovered in the doing. While we may struggle as physicians with poor outcomes and our own limitations we must always remember that the patient comes first. We may not be able to offer the patient an operation, but there remains the opportunity to care for the patient, to help relieve their symptoms by other means and to help to improve the quality of the time they have remaining. By utilizing the principles of palliative care the surgeon and all

physicians can continue to uphold their duty to the patient to relieve their suffering and not abandon them; ensuring that patients know they have the empathy of their physician and that they will be present to shepherd them through this challenging time (19,25).

Conclusions

Sadly, Mr. Jones is not an uncommon patient seen by surgeons. He is also one of the most challenging encountered in surgical practice. While in desperation he may express a strong desire to do anything to treat his cancer, his surgeon must determine what treatment options are even available to him. In medicine a patient's autonomy is the basis of decision making, but there remain many other factors that the physician is responsible for in this process. The physician needs to ensure the patient truly understands, taking the time when needed to counsel and listen to patients so that they can make informed decisions that correspond with their goals and values. At the same time, there are many personal factors (e.g., commitment to the Hippocratic principles of beneficence and non-maleficence, surgeon autonomy in the operating room, non-abandonment) the surgeon faces that while not always discussed with their patients impact the surgeon, especially when contemplating surgical intervention in advanced illness. For surgeons taking care of patients facing the prospect of a palliative procedure or any surgical intervention at the end-of-life, there remains a lack of scientific data to guide decision making. Once a decision has been made, the surgeon retains a sense of responsibility to the patient to care for them not just during the operation, but afterwards. The unfortunate reality for patients in these situations is the poor outcomes many face and even though surgeons' strongest desires are to fix their patients, death cannot be 'fixed'. Ultimately, one must remember that often what patients near the end-of-life need most is for their physicians and surgeons to be sources of support during this time.

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Footnote

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