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End of Life Planning and its Relevance for Patients and Oncologists' Decisions in Choosing Cancer Therapy

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Abstract

The goal of end of life (EoL) planning is to provide individuals with tools to control their financial and health care decisions when they are incapacitated. When an elderly patient is diagnosed with advanced cancer, the possible treatment options are: palliative care with curative intent or prolongation of life or palliative care only. Treatment of cancer in elderly patients creates a significant array of monetary and symptom burdens. The question is whether advance care planning (ACP), part of EoL planning, allows patients families and communities to control and reduce these burdens.

Although the number of patients completing advance directives has increased in recent years, there are multiple barriers to the implementation of patients' wishes such as limited knowledge of patient wishes by proxy and physician and inadequate communication regarding prognosis. We propose that improvements in patient decision making and clinical practice can reduce the burden of symptoms for patients if clinicians better understood patients' models and expectations respecting the longer term consequences of diagnosis and treatment. This understanding can arise from improved information exchange and constant updating of the information as the disease and treatment evolves. Clinicians also need better prognostication tools and better training in effective communication skills to elicit patient goals and make appropriate recommendations.

Keywords

End of Life Planning; Advance directive; Palliative Care; Patient-physician communication

Mr. Z, a 70 year old, active male with a history of smoking and COPD presents to his oncologist for evaluation and treatment of his newly diagnosed non small cell lung cancer (NSCLC). He has never had any acute, life threatening medical illness. His wife and his daughter accompany him for this visit. Mr. Z states that he "had been worried that his condition could be serious, and is ready to go under the knife

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and have it cut out.” He does not have any advance care planning for health or finances in place. He is unclear how the treatment will impact his finances and add new burdens for his wife and family.

He has heard of cancer treatments including surgery, radiation and chemotherapy, but has no knowledge of its indications and likely effects on cancer and his daily function.

Prior to the end of the interview, Mr. Z asks “How long do I have to live?”

The above scenario is part of the everyday experience of many oncologists. Mr. Z is typical in that cancer is primarily a disease of the elderly; age therefore, is one of the most potent risk factors for the disease¹. Even with the new advances in early detection, many cancers are still diagnosed at an advanced stage¹. The new advances in drugs and targeted therapies have increased the likelihood of survival for many patients with cancer². While these improvements are important, much remains to be done to understand and better manage the losses of physical and mental function and the emotional and financial burdens that cancer and treatment create for patients, families and society. Direct and indirect monetary cost from treatment, premature death and loss of productivity of patients and caregivers are easily estimated³. Patients’ emotional distress and worries about the burdens of symptoms, pain, and loss of function from cancer and treatment are far more difficult to calculate.

When cancers are detected late, patient survival is in months², and these estimates are often optimistic for elderly patients who have co-morbid conditions. Treatment for advanced disease may offer very limited gains in survival time with satisfactory function and be outweighed by the burdens created by time in therapy, and the uncertainty, worry, and distress, experienced by the patient^{4,5}. Would advance planning, i.e., the completion of advance directives, make a difference in the decision process? Would it improve the treatment decisions and minimize the emotional distress and uncertainties that may be part of the final period of life for Mr. Z and his family? Answers to these questions can be judged by reviewing data from epidemiological and health services studies and what we know about the decision process.

End of Life Planning and its impact on Cancer Treatment

End of life planning is presumed to provide individuals with tools to control their financial and health care decisions at a point in time when they can fully participate in decision making. The four components of end of life planning are: 1) completing an advance directive (AD) or living will, 2) appointing an individual with durable power of attorney for health care, 3) having a document for distribution of assets, and 4) specifying preferences for type and place of care. We will focus on the living will and durable power of attorney for health care (DPAHC).

The goal of Federal statutes such as Patient Self Determination Act (PSDA) and regulations enacted in all fifty states calling for the preparation of advance directives or “Living Wills”⁶, was to encourage discussion among patients, caregivers, and health care providers to clarify patient preferences for end-of-life care and medical treatments if and when the patient is incapacitated and unable to make decisions⁷. The ultimate objective is to enhance the conditions for a death that is as free of pain and suffering as possible⁸. Studies find that patients view the AD as a way preparing for their future incapacity and death in conjunction with loved ones⁹. For many patients the objective is to minimize the burden of death on loved ones rather than to maintain their autonomy⁹. Specifying a health care surrogate to make decisions about medical care (naming a DPAHC) is another way of preparing for possible future incompetence and/or incapacitation¹⁰.

Do patients engage in end of life planning?

AD cannot achieve their objectives if they are not completed. National surveys report considerable variability in the proportion of respondents who have considered, begun and completed an AD¹¹. Completion of Advance Care Plans (ACP) increased from the time prior to the passage of the Federal PSDA mandate when only 21% of hospitalized, seriously ill patients had an AD¹² (early 1990s), doubling to 40% of the over 70 year old respondents in a nationally representative sample interviewed in the mid 1990s¹¹. A 2003 report from the Agency for Healthcare Research and Quality (AHRQ) reported that somewhat less than 50% of severely or terminally ill patients had an AD in their medical record¹³. Patients that have completed advance directives tend to be white, educated, and from upper socio-economic categories, living in nursing homes or dying from cancer. Non-white and non-anglo ethnic groups are less likely to have completed living wills, to have engaged in discussions with family about end of life health plans, and less likely to have named a DPAHC¹⁴⁻¹⁷.

Do Family and Clinicians understand patients' AD?

Even when completed, AD cannot meet their objectives if patients and families do not understand how they are to be used. Many patients complete AD in conjunction with planning for the disposal of valuables, property and finances after death. In contrast to the attention to detail patients appear to give to the disposal of assets; few appear to consider how their AD will be used when completing it. As gifting and financial planning occur throughout life, patients are far more likely to be familiar with these actions and decisions than the actions and decisions surrounding dying, a process with which they may have little objective and no personal, subjective experience. The implementation of an AD requires that family and clinicians know that it exists, how the patients interpreted the questions and the meaning of his or her answers. Data suggests this often fails to happen. In several studies, approximately 28-30% of respondents had not discussed their advance care preferences with family members, and up to 91% of the patients had not discussed it with their physicians¹⁸⁻¹⁹. Without the knowledge and understanding of a patient's advance directive, family and clinicians have to substitute their judgments for that of the patient which creates a serious limitation to implementation of patient's AD.

Do the Questions in Living Wills Address Key End of Life Issues? Is it reflective of patient's preferences?

Available evidence indicates that people wish to limit and indeed to avoid specific treatments such as intubation and cardiopulmonary resuscitation at the end of life¹¹. A reading of the publicly available Advance Care Directive for the State of New Jersey (see appendix for link), which is typical of such documents, raises questions as to whether a patient's responses will provide guidance for end of life care that will be experienced as meeting the patients' preferences for a death that is free of pain and suffering. For example, one paragraph of the document reads: "If I am diagnosed with... incurable and irreversible illness... my condition is terminal... I direct that life sustaining treatment be withheld or withdrawn." First, this presumes that the patients' responses are based upon an accurate anticipation as to what they will want during the final period of life;²⁰ i.e., that patients can foresee or prognosticate how functional they will be, how much pain and distress they will experience, and how their chosen proxy and other family members will be able to tolerate observing them in that condition. Reflecting on the conversation with Mr. Z above, his readiness to "go under the knife" and question "how long do I have to live?" suggests he views his condition as curable (cut it out) on the one hand, and fatal on the other, with few images of anything between. It is not at all clear that had he completed an advance directive prior to diagnosis that it would have reflected any decisions he would make right now for his treatment.

Second, the generality of the questions assumes that a patient's preferences for care at the end of life will be the same for different incurable and irreversible diseases (i.e., advanced cancer, end stage cardiac disease, end stage kidney disease, etc),²¹ and that practitioners will discuss benefits and burden in understandable language for disease specific treatments.

In several studies, many patients chose active cancer therapy for seemingly small benefit irrespective of potential toxicities in comparison to matched oncology clinicians or patients with COPD ^{22,23}. It is unclear whether patients facing diagnosis and the possibility of death choose therapeutic options differently than patients not facing that threat. In addition, it is not clear that the differences in choices made by non-cancer and cancer patients would hold for within person comparisons, i.e., between decisions made by the same individuals when well and when in cancer treatment. Patients may also accept and adapt to functional changes such as needing assistance for toileting that they earlier rejected, as they transition through disabling disease and treatment.

These studies raise an interesting question as to whether an individual's expectations about distress and self-competence at the end of life and their expressed treatment preferences change after being diagnosed with cancer. Preferences for care change with experience and are expressed in different degrees of detail from early to later in life²⁴, and from pre to post hospitalization²⁵. These changes require updating of AD to reflect patients' newly formed expectations of their future experience; the implications are of special importance for the practice of oncology.

Like Mr. Z., virtually all patients with metastatic malignancies have incurable and irreversible disease and many treatment options offer minimal benefit (less than 10% response rates or few days to weeks of prolonged survival)^{26, 27}. The discussion between patient and the oncologist includes potential benefits and toxicities for the typical case and may be presented in general rather than specific language, but the benefits and the toxicity and how they will be experienced by this particular patient are unknown a priori. From the cognitive science perspective, the sharing of information and values reflected in a patients' AD takes place in a context of two separate models of disease. The model for the patient is based on their previous experience and observation of illnesses in others, and abstract knowledge about cancer and cancer therapies. The oncologist's model consists of abstract knowledge of the disease and therapeutic options and toxicities, and concrete experience with other patients in similar situations; these models are likely far more detailed and differentiated than patients models. The oncologist however, lacks access to the patient's own and observed experiences with illness in self and others. The decisions that arise from the patient-physician communication, or "shared decision making" reflect the extent to which information has been exchanged from the abstract concepts into patients' model, and from the more concrete experience components of each participants' model. The lower rates of choosing chemotherapy by clinicians in the above study, in comparison to cancer patients, may reflect clinicians' greater abstract knowledge that allows them to make more accurate self prognoses of treatment benefits. However it may also be possible that they are not experiencing the concrete physical changes and psychological worries and fears associated with the possibility of certain death that motivate choosing treatment²². Unfortunately, the conversations necessary for updating AD may occur without the clinician perceiving the patients' experiences with disease and treatment and the motivation to opt for intensive treatments that yield little gain. Discussions regarding therapies and updating AD may take place without either party understanding what the other means by "terminal" and "medically necessary" when choosing among options such as palliative care and chemotherapy.

The choice of palliative care as directed in the ACP, has been shown to reduce the symptom burden by improving symptom control and honoring patients wishes regarding place of

death²⁸. How to conduct and constantly update ACP to incorporate the knowledge and experience of disease and treatment poses a challenge for clinicians, patients and researchers studying the impact of ACP on the symptom burden at the end of life.

End of Life Decisions and Planning: An Updating Process

Forecasting future pain and disruption of function from disease and treatment involves enormous uncertainties that vary by specific disease, its stage and aggressiveness. For example, end stage experience with prostate cancer will differ from that of colon cancer, and both will differ from congestive heart failure. Prognosticating however, is clearly fundamental to the completion of living wills and discussions of end of life preferences and each participant brings their own motives and biases to the process. The prognosticator role is often unwanted by the clinician²⁹ as prognostications are often inaccurate given the vagaries of a disease and its response to treatment. Prognostication is also difficult for the patient. The life context and “subjective data,” i.e., experience with illness, that patients use in forming end of life preferences will change as they experience the somatic and functional changes of aging and the impact of specific disease and treatments.^{25, 30} Thus, the evidence they will use when expressing end of life treatment preferences years and even decades in advance of diagnosis and treatment may overlap relatively little with the subjective data they will use at advanced ages and at the end of life. In addition, both the early and later life experiences of the patient may coincide relatively little with the evidence used by clinicians for making end of life treatment decisions.

Behavioral Science Perspective

Are there theoretical models and practical procedures that can assist investigators and practitioners to better conceptualize how patients and families formulate their expectations (i.e., prognostications) of the self in the end of life setting and how these expectations affect the preferences they express in advance directives? Awareness of and ability to address the differences between lay and medical perspectives will shape how advance planning is conducted. An example of how theory and practice might be integrated is illustrated by considering the subsequent, hypothetical encounters between Mr. Z and his oncologist.

Recalling the first meeting it is clear that Mr. Z’s oncologist faced multiple tasks. First, the patient and family had to be educated about the current status of his disease, that it was metastatic and incurable; second, they had to be informed of available treatment options and the expected benefits and toxicities of each. The oncologist also needed to encourage Mr. Z to develop his advance directives and designate a person as his proxy decision maker.

The oncologist can be effective in helping Mr. Z achieve a deeper appreciation of his disease as incurable by recognizing that Mr. Z’s experience based knowledge is both limited in scope and potentially a source of inaccurate expectations. Mr. Z’s hope that his tumor can be cured by “cutting it out” is consistent with his and most people’s prior experience with illness³¹, and with the view of cancer as a localized and contained growth. Helping Mr. Z to understand that cure by surgery is inconsistent with disseminated disease opens the door to understanding treatment options that can attack a tumor in multiple locations. It also allows Mr. Z to begin to more fully grasp both the potential gains and toxicities of each treatment option, and how these toxicities will be experienced and impact his daily functioning. A conversation between the oncologist and Mr. Z needs to align their separate views on these points as clarifying the patients’ expectations is essential for setting the goals for therapy.

Treatment options for a patient such as Mr. Z range from standard through investigational therapies with palliative care or palliative care alone. The oncologist lacks specific prognostication tools (except for performance status) to help make optimal decision for Mr.

Z; her task is to estimate gains in life extension and physical and psychological function against the burden of toxicities for each therapeutic option. The oncologists' estimates are based on published clinical trials usually conducted with younger patients with less co-morbidity. Instruments such as the Comprehensive Geriatric Assessment, co-morbidities index and others in development may help oncologists and patients with these decisions³². Palliative care only would be an optimal choice if both patient and oncologist believe that the chemotherapy would not achieve patient's goals. In addition, the oncologist and perhaps Mr. Z himself, lack both the objective and subjective data needed to predict how Mr. Z and his family members will respond emotionally and behaviorally to treatment.

From the patient perspective, Mr. Z wants to understand what it means to have this cancer and how treatment can help. His ability to process and generate meaning from the oncologist's statements is shaped by his knowledge, i.e., his limited concrete experience with disease and treatment, limited abstract bio-medical knowledge, and by his need to maintain emotional balance following recognition that his cancer has spread and is incurable. It is unclear how much of the information that was conveyed after that point such as treatment options, potential side effects, is heard, recalled and understood; and how many of these words were translated into specific anticipations of what he will later experience and how best to prepare and respond when they occur. The content (what side effects he may experience) of these anticipation and how they are framed (do they mean pain and distress or do they indicate a degree of control of disease and additional viable time of life) affect later emotional response to and evaluation of treatment^{33, 34}.

Ambiguities exist when Mr. Z asks how long he will live; does the question reflect a hope for cure, or the wish to attend a grandchild's wedding six months from now? Predicting the future is fraught with uncertainties for all parties and uncertainties may lead to guardedness in prognostication and constraints in communication. The oncologist does not want to make optimistically inaccurate predictions of life span and lose the confidence of the patient and family, and look foolish to colleagues nor does the oncologist want to make too dire a prediction and risk destroying hope and motivation for making the most of his remaining days. Aggressive treatments chosen by cancer patients are inconsistent with data from economic studies showing that people will discount future rewards (gains in life time) for current benefits (avoiding severe distress of treatment)³⁵. However, if Mr. Z and family have been planning for a specific event such as their grandchild's wedding, an event that may be remote in "objective" time relative to disease status, may appear close in subjective time, and not be discounted as is typical with future rewards, leading to decisions for aggressive treatment with relatively low probability of success.

Without the above knowledge exchange, a patient may not have the same understanding of the disease as the oncologist and the oncologist may not have a good understanding of the concrete features and abstract notions that form the patient's perspective of treatment, his subsequent function, and duration of life with family. If by chance Mr. Z had an AD, it would need to be updated, i.e., the living will and the assignment and role of a decision making proxy, this latter process will require additional time and meetings. Mr. Z, his family and oncologist agreed that chemotherapy treatment would likely provide the best combination of survival, satisfactory daily quality of life and a chance to attend his granddaughter's wedding. Chemotherapy was set to begin in two weeks.

Mr. Z and his wife came in a few days prior to his scheduled visit for chemotherapy because he had been coughing up blood. Chemotherapy was delayed and radiation therapy was recommended and begun after detailed discussion of possible side effects such as fatigue, the major negative factor, skin rashes, a lesser concern, and possible organ damage. Given the concern of family and the oncologist at the amount of bleeding, Mr. Z and his wife quickly accepted radiation and expressed

their hope that it would stop the bleeding. The symptoms, and not hopes for survival, motivated the decision.

A few weeks after starting the radiation, Mr. Z stopped going to work due to fatigue. His fatigue and increased debility led to the decision to delay chemotherapy until he was more functional.

The differences in the anticipated and observed effects of radiation on his function were discussed at a subsequent visit. Despite the best efforts to prepare Mr. Z and his family for fatigue, the degree to which it disrupted Mr. Z's daily function exceeded both his and families' expectations. Given his goal to attend his grand daughter's wedding a few months later, after discussion among all parties of possible toxicities and benefits, chemotherapy was recommended and started. The decision to treat was based on the congruence of medical and family benefits.

Mr. Z's fatigue improved over the next two weeks, he began chemotherapy on a clinical trial. Chemotherapy required weekly visits to the cancer center for blood work and/or therapy. They were concerned about his fatigue and inability to do things around the house. During first few months of therapy, Mr. Z's symptoms had greatly improved; he was energetic and able to work 1-2 days a week for 3-4 hours a day, the maximum possible with his chemotherapy schedule and fatigue. The interim CT scans showed improvement from both radiation and chemotherapy. Contact with friends and people at work had improved his and his family's spirits. He had completed an Advance Directive with his wife as HCP that indicated that he would wish to withhold or withdraw life-sustaining treatment for all of the choices in New Jersey Advance Directive. He had discussed the rationale for making these choices with his oncologist as well. The discussion with oncologist had involved specifics on likely outcomes of specific interventions such as mechanical ventilation as well as cardiopulmonary resuscitation.

Between months 4 and 5, he became increasingly fatigued, lost weight, had little appetite, and stopped going to work. The concern about decreased energy and weight loss was discussed as well as whether continuation of chemotherapy was in congruence with his desire for quality of life. His goal was still to attend the wedding he wanted to "fight" through the therapy and was seen by a nutritionist and prescribed an appetite stimulant. Two weeks later, he was admitted to the hospital with fever and hypotension requiring ICU admission. A CT scan performed during the hospitalization showed progression of his cancer. The oncologist, patient and family discussed the results and implications. Various choices for future treatments including hospice care were discussed. A detailed discussion included the likely outcomes with possible toxicities of each. With his strong desire to attend the wedding in a few weeks and hopes that he would regain some of his strength just as he had done after radiation therapy, he chose rehabilitation followed by additional chemotherapy.

After discharge from the rehabilitation unit, he was seen in the office where he complained of shortness of breath. He was referred to the emergency room for evaluation and was found to have a pulmonary embolus. During this hospitalization, discussions regarding future care were discussed and given his continued decline in function, limited quality of life and limited benefit of available chemotherapeutic options, hospice care was chosen. Patient died a few weeks later at home.

To ensure that Mr. Z received the care he wanted and preferred, the knowledge exchange that occurred at the first visit needs to occur at each subsequent encounter. Mr. Z's goal at the beginning of this encounter was to attend his grand daughter's wedding in few months. It

is unclear whether that goal remained the most important goal throughout his disease trajectory. The implications of decreased energy, weight loss, hospitalizations and subsequent rehabilitations may have led him to reformulate what is important to him.

Summary and Recommendations

Patients with advanced cancer, many of whom are elderly have a significant symptom burden associated with cancer and its treatment. The benefit of end of life planning on symptom burden is mixed at best. ACP has underperformed its hoped for benefits of a death free of pain and suffering with maximum possible quality of life, as many people do not engage in planning and those who do often fail to adequately engage those selected as surrogates in their decision making process.

For most patients, the formulation living wills and selection of a proxy decision maker, is performed in the absence of knowledge and understanding of the specifics of the treatments and subjective experiences at the end of life. Planning by patients and families is based upon limited subjective and objective knowledge gleaned from their own illnesses and observations of illnesses in others. Prior to the onset of infirmities and chronic conditions of later life, most persons hope and expect illnesses to be symptomatic, short lived and curable with treatment, i.e., acute illness is the default model for understanding diseases and forming treatment expectations³¹. This underlying model supports the hope for cure that is visible in many end-of-life decisions. Without the personal experience of the series of events beginning with the diagnosis of cancer and ending with death, patients and families will very likely lack valid, detailed images of the complexities inhabiting the intermediate domain of the difficult and prolonged management process that is typical for many cancer patients.

Each of the issues we have covered can be discussed from three perspectives: 1. Behavioral theories that focus on how individuals make and share decisions; 2. Clinical practice; and 3. public policy.

The oncologist has the experience and knowledge of the prototypes or illness models that define the poles of acute and curable and chronic, fatal illnesses. The oncologist also has intimate knowledge of the treatments to extend survival but is at best only partially aware of the impact of the uncertainty and the compromises of reduced function, emotional distress, and lowered quality of life as experienced by a specific patient. The oncologist needs to frame expectations of treatment for survival and toxicity in the context of the models that patients and families are using to make decisions for therapy. The oncologist who both listens and possesses the communication skills to explore the patient and families perspectives and the skills needed to bring his knowledge to the conversation in an understandable manner, is more likely to be successful in helping patients meet their goals. The oncologist can achieve this by helping patients and family update their perceptions of disease and treatment and formulating new preferences, valid expectations and decision that are more effective for a death free of pain and other symptoms.

We see three areas for developing policies to encourage new approaches that will increase the effectiveness of end of life planning in meeting the needs of patients and society. One involves mandating and funding opportunities for up-dating end of life directives. Updating however will be ineffective in the absence of discussion between patients, families and practitioners. Meetings should be required for discussion of concerns respecting disease and treatment. Such meetings must cover patient's personal experience, likely impact of treatments on function, emotional distress, quality of life, and likely gains in time with acceptable levels of function.

Policies must also require changes in practitioner performance; it is insufficient to frame policies solely for patients and families. These policies will include changes in medical education and updating how practitioners frame their exchanges with patients. Though “being nice”, respectful and a good listener are essential, more is required. Practitioners need a framework that allows them to effectively communicate and explore how a patients and families perceptions and beliefs about disease and treatment affect how they process the information given them by oncologists and how they interpret and assign meaning to their ongoing experience with disease and treatment. The understanding emerging from these processes affects patients’ treatment preferences and decisions³⁶. Patients can frame these gains and losses abstractly, as days and weeks alive, or concretely, in realistic view of function and surviving to experience significant life events that have a reality that is vivid and worth fighting. Policy must call for and implement educational experiences to achieve this goal.

Finally, policy makers need to advocate research that will provide new insight into the process of preparation for the end of life experience. Research must be guided by two masters: theoretical models in the behavioral domains of communication, information processing and decision theory, and clinical experience of oncologists and their patients. Success requires the integration and shared insights of practitioners from behavioral and practice disciplines with that of patients and families³⁷. Research from a single disciplinary silo will not move us forward in understanding or practice for a more humane approach to the final interval of valued lives.

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