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Toward Ethically Responsible Choice Architecture in Prostate Cancer Treatment Decision-Making

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Medicine operates under an assumption that "patients will naturally gather evidence about the risks and benefits of each medical choice, apply their values to that evidence, and reach a considered decision."[1] In other words, that patients will generally make "autonomous" decisions, meaning decisions that are a.) intentional rather than habitual, impulsive, accidental, or forced, b.) involve substantial understanding of the nature of the decision, the foreseeable consequences and possible outcomes, and c.) are not subject to controlling influences.[2]

While this assumption has been challenged in other areas of medical decision-making[1], here we want to challenge it in the context of treatment decision making about localized, low risk prostate cancer. Many men will face this decision given that there are 220, 800 new cases of prostate cancer each year in the U.S.[3] Yet, there is alarming evidence to indicate that patients may not be properly informed about their options, particularly expectant management options such as watchful waiting or active surveillance. And there is further evidence that men may be especially prone to using intuition, impulse, and "heuristics" or mental short-cuts in their decision-making[4], all of which threaten autonomous decision-making.

Two recent papers in this journal highlight the complexities of treatment decision-making in low risk prostate cancer.[5,6] As Filson, Marks, and Litwin note in their article on "Expectant Management for Men with Early-Stage Prostate Cancer" in this issue[5], men with a new diagnosis of localized prostate cancer face an array of treatment options, each associated with high disease-specific survival given the slow growing nature of many prostate cancers. Radical prostatectomy and radiation therapy are the most commonly utilized treatments for localized prostate cancer, and each has associated treatment-related complications that impact men's quality of life. Increasingly, active surveillance is being recommended by clinical guidelines as a treatment option for men with low risk disease.[4] Unlike watchful waiting, active surveillance involves careful monitoring of the disease with an expectation of curative treatment if there is progression. While active surveillance has disadvantages of

periodic testing and associated anxiety, the major advantage of active surveillance is the preservation of current health and avoidance of treatment-related complications including impotence, urinary, and rectal incontinence.

Despite the appropriateness of expectant management strategies such as active surveillance for early stage prostate cancer, as highlighted by Filson et al. in their article, men who might benefit from expectant management are not routinely offered the option. Other studies have reported similar findings. One study found that only 10 of 25 early stage prostate cancer patients were offered a treatment choice[7]; another found that of 21 men (19 of whom chose surgery or radiation) few remembered active surveillance being presented as a viable option[8]; and another found that health professionals were less likely to discuss active surveillance for localized prostate cancer with Hispanics compared to Whites.[9] Further, studies have found biases and heuristics at work in patients' decision-making (all favoring surgery or radiation) such as the "commission bias" (doing something is better than "doing nothing" even if the "something" causes more harm)[8] and the "availability bias" (reliance on anecdotal stories),[10,11,12] in addition to fear[10,11,12,13], heavy reliance on physician recommendation[4,8,10,12], reported pressure from family[4,8], and lack of awareness that treatment does not guarantee improved survival.[10,11]

These findings about prostate cancer decision-making are ethically significant given that they imply that prostate cancer decision-makers may not be as autonomous as we would assume. They also raise concerns about patient well-being given the risk of harm associated with surgery and radiation. An 8 year follow-up study of 272 men showed men who had surgery consistently reported more urinary leakage, impaired erection and libido[14]. Findings from the Prostate Cancer Intervention versus Observation Trial (PIVOT) showed higher rates of urinary leakage and erectile dysfunction among men randomized to receive radical prostatectomy compared to men observed.[15] Higher rates of urinary leakage among men assigned to radical prostatectomy versus watchful waiting were observed in the Scandinavian Prostate Cancer Group Trial Number 4.[16,17,18] While randomized trials comparing radiation therapy to expectant management are lacking, evidence from observational studies shows an increased risk of erectile dysfunction in radiation therapy patients compared to watchful waiting patients.[19,20,21] Finally, these findings have important implications for societal costs as well. It has been estimated that if half of recently diagnosed low-risk men opted for observation, the health care savings would surpass $1 billion in the U.S. per year.[22] Moreover, according to current U.K. National Institute for Health and Clinical Excellence (NICE) guidelines issued in 2008, active surveillance should be the preferred treatment for low-risk patients.[23] And both the American Urological Association (AUA) and the National Comprehensive Cancer Network (NCCN) have issued guidelines that stress the importance of assessing life-expectancy in the decision-making process given that the survival benefits of immediate treatment may not be realized for many years, if ever.[24,25] Despite all of this, only 20–30%[26,27] of eligible men are on active surveillance protocols.

In their conclusion, Filson et al., argue for a shared decision-making process where patients are presented with information about the risks and benefits of expectant management including the use of patient decision aids.[5] Also in this journal, Violette et al., reported a

systematic review of randomized trials of patient decision aids for localized prostate cancer treatment.[6] It is important to note that the aids included in this review did not define or distinguish active surveillance or watchful waiting because they were developed before publication of large trials such as the Prostate Cancer Intervention versus Observation Trial (PIVOT).[15] Among the 14 trials reviewed by Violette et al., the use of patient decision aids had no impact on treatment choices.[6] Decision aids have long been seen as adjuncts to clinical encounters, preparing patients to participate in clinical decision making with the health care providers with the goal making decisions congruent with patient's values.[28] Clearly, the use of patient decision aids alone will not be sufficient to raise the profile of expectant management for prostate cancer treatment for patients who might benefit from it. Furthermore, their use among specialists treating prostate cancer patients is relatively low.[29]

Ethically Responsible Choice Architecture

We propose that a beginning solution to the current situation in prostate cancer decision-making is for clinicians to engage in what we call "ethically responsible choice architecture." Choice architecture is a term coined by Richard Thaler and Cass Sunstein to refer to the organization of the context in which people make decisions. Thaler and Sunstein stress that the design of the choice context is important and unavoidable such that, "If you are a doctor and must describe the alternative treatments available to a patient, you are a choice architect."[30] The question then becomes how clinicians can engage in choice architecture around prostate cancer decision making in a way that is ethically responsible given what we know about how patients make decisions in this context. The current context is one that heavily favors immediate intervention. Thus, ethically responsible choice architecture would encourage men to seriously consider the harms/cons of immediate intervention and also the pros/benefits of active surveillance.[31] This applies not only to clinicians but also to developers of decision aids for localized prostate cancer treatment (see Violette et al. in this journal for a systematic review and meta-analysis of prostate cancer decision aids).[6] This could be accomplished using several techniques: (1) framing insights, (2) social norms, and (3) narratives.

1. FRAMING OF OPTIONS

When clinicians deliver options and information to men about how to deal with their newly diagnosed prostate cancer they have to make several decisions about how to frame that information (e.g., the order in which to deliver it, whether to frame numbers in terms of frequencies vs. percentages, whether to frame risk in absolute or relative terms, whether to frame information in terms of gains such as survival rates or losses such as mortality rates, etc.). But at a very basic level, they have to make a decision about how to frame the initial decision: they can frame the decision as immediate intervention vs. active surveillance ***or*** as open surgery vs. laparoscopic surgery vs. robot assisted surgery vs. 3D radiation, vs. intensity-modulated radiation, vs. proton radiation vs. brachytherapy vs. cryoablation vs. active surveillance. The former framing is preferable both because it simplifies the initial decision for patients and avoids tipping the scales heavily towards immediate treatment as the latter framing does. Another important technique that clinicians can employ to frame the options in an ethically responsible manner is to avoid presuming intervention as the default

by asking men *which* treatment intervention they prefer (e.g., surgery or radiation). Instead, active surveillance could be framed as the default, communicating to appropriately selected men that they could begin an active surveillance protocol and that they have time to decide whether and when to opt into more invasive management. Default options are so powerful that they even impact people's end of life decisions. One study found that when life-sustaining treatment was assumed the default in an advance directive document, 38% of people favored treatment, and when non-intervention was assumed the default only 20% favored treatment.[32]

2. ENGAGING SOCIAL NORMS

A second technique for ethically responsible choice architecture in prostate cancer decision-making is to show patients that some men (e.g., a public role model[33]) do choose active surveillance and this can very well be considered a "normal" or reasonable choice. For example, one study of 331 prostate cancer survivors found that a normative message of "You don't have to panic… You have time to think about your options" was perceived as believable, accurate, and important to hear by over 80% of men. 60.4% believed that this message would make men more likely to choose active surveillance. The message rated the highest in terms of likelihood to impact choice was "As long as I'm keeping a close eye on it with my doctors, I can possibly prolong this for a number of years until the treatment options have improved." 77.3% believed that hearing this message would make a man more likely to choose active surveillance.[34] Moreover, because physician recommendations create powerful social norms, physicians should avoid recommending surgery or radiation as the only reasonable choices for patients with low-risk localized prostate cancer. They may even positively recommend active surveillance as an option to think seriously about.[35]

3. USE OF NARRATIVES

A third technique for ethically responsible choice architecture in prostate cancer decision-making is to make the potential harms for surgical intervention or radiation more realistic and salient to patients. Although men state that side effects are important, a systematic review of prostate cancer decision making found that these same men do not report that consideration of side effects actually influenced their ultimate decision.[36] Patients may intentionally or unintentionally minimize side effects, or side effects may be presented too abstractly.[36] Narratives (textual or video) are ideal for helping patients to imagine health situations that they have not previously experienced.[37]

Objections and Replies

There are two major objections to our proposal. One is that individual patient preference and patient autonomy is an important component of prostate cancer decision making that our proposal misses or deemphasizes. The second is that our proposal assumes that avoidance of immediate treatment is in patients' best interest, but there are reasons to question this. Let us address each in turn. Regarding the issue of the role of patient preferences and patient autonomy, we want to emphasize two things. First, our articulation of ethically responsible choice architecture is just that: an articulation of choice architecture. The ultimate choice is the patient's, within the context of the physician-patient relationship, and all options need to

be presented to and discussed with the patient. Patients who prefer surgery or radiation are free to, and will, elect those treatment options. Second, our proposal takes into account that the current choice architecture heavily favors immediate treatment and involves several factors in decision-making that are *not* conducive to autonomous decision-making (e.g., lack of information about all of the options, biases and heuristics heavily favoring immediate treatment, the diagnosing physician might also be the treating physician, etc.). Our proposal attempts to counter the existing choice climate so that expectant management is seriously considered as an option and the risks and side effects (not only the benefits) of surgery and radiation are understood and appreciated. We believe this is the ethically responsible thing to do given that the current climate so heavily favors immediate treatment and given that clinicians are ultimately responsible for creating and managing choice contexts for patients.

Regarding the issue of what is in patients' best interests, we do *not* assume that expectant management (or immediate treatment, for that matter) is in all patients' best interest, since what is best for each patient depends on their preferences, values, and trade-offs (prostate cancer management truly is a preference sensitive decision). Instead, we recognize that expectant management *may* be in some men's best interests —much more than the small proportion of newly diagnosed men who are actually on active surveillance protocols. Five year outcomes reveal that while both immediate treatment and active surveillance groups have equal amounts of health-related distress, worry, feeling low, and insomnia, the intervention group (mostly surgery) consistently reported more urine leakage and impaired erection and libido.[38] A recent systematic review of the impact of active surveillance on quality of life identified ten observational studies with follow-up periods ranging from 9 to 36 months.[39] Patients undergoing active surveillance reported good overall quality of life without negative psychological impacts. It was also concluded that longer follow-up data was needed to identify reasons for leaving active surveillance protocols and long-term impact on quality of life. Moreover, studies have shown that active surveillance does not necessarily produce anxiety harms[40] or decisional regret.[14] Thus, it is likely that expectant management strategies such as active surveillance *may* be in the best interests of some men with low-risk, localized prostate cancer, despite that fact that they often do not consider it a viable option, or it is not presented as such. The crux of our proposal is that ethically responsible choice architecture does not occur in a vacuum and instead needs to account for known facts about the current context in which this decision occurs, both on the clinician end and the patient end.

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