

The road not taken: Forgoing disease-directed treatments in advanced cancer. A rejoinder to ‘Concepts of health, ethics, and communication in shared decision making’ by Lauris Kaldjian

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1. Introduction

Between 1961 and 1979 physicians changed their practice from most often *not telling* patients their diagnoses of cancer to routinely *disclosing* it (Oken 1961; Novack *et al.* 1979). The change can be explained, in large part, by advances in cancer treatment, growing appreciation of the duty to obtain informed consent, changes in professional values, and the rise of the patients’ rights movement. It soon became apparent, however, that patients with advanced cancer were often unaware of their prognoses because *prognostic disclosure* was far more challenging to physicians than diagnostic disclosure. In 1995, investigators of the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) reported that an intervention to inform physicians of prognostic estimates and a nurse to elicit patient preferences and encourage patient–physician communication did not improve the frequency of code status discussions, physician awareness of patient resuscitation preferences, or number of days in the intensive care unit (ICU) (Connors 1995). In reflecting on the progress between the publication of the SUPPORT study and the 2015 Institute of Medicine report *Improving Quality and Honoring Individual Preferences near the End of Life*, we wondered whether the persistent concerns about the quality of end-of-life (EOL) care and patient awareness of prognosis are due to flaws

in clinician appreciation of the ethical principles of informed/shared decision making or clinician communication skills.

2. Kaldjian’s essay

A similar question interests Kaldjian in his essay ‘Concepts of health, ethics, and communication in shared decision making’ (Kaldjian 2017): how do we resolve the ‘disagreements about what is good for a patient in a given circumstance, disagreements that manifest as questions about preferences, goals, and ethics’ (Kaldjian 2017: 83)? We accept the two major premises of the essay. First, Kaldjian proposes that disagreement (and agreement) is situated within a ‘purpose-oriented landscape’ in which healthcare decisions are ‘shaped by a stream of intentionality that connects treatment and tests, goals of care, values, health, and ultimately a vision of flourishing’ (Kaldjian 2017: 83). Second, the potential sources of disagreement are differences in clinicians’ or patients’ concepts of health (biostatistical or well-being) and the different limits to ‘shared decision-making as it is usually conceived’; namely, limits to patient autonomy and clinician persuasion. The claims we wish to evaluate more fully are the implied claim that the goal of shared decision making is agreement and the explicit claim that goals of care are a helpful and necessary means to resolve patient–clinician disagreement.

3. Ethics, shared decision making, and the patient's experience

We find that a recent paper (Irby and Hamstra 2016) summarizing the evolution of how we think about professionalism in medicine – starting with the first American Medical Association (AMA) code of ethics (1847) and continuing into the late twentieth century – is informative to the current discussion. At first, professionalism was viewed as residing in the individual who aspires to, and acts in accordance with, timeless ethical principles and codes of conduct. The second era began in the late 1990s when organizations such as the Accreditation Council for Graduate Medical Education recommended that all trainees be assessed in six core competencies including professionalism and communication. The introduction of competencies necessitated the development of models of professional *behavior* to educate trainees and methods for measuring behaviors as more or less professional. The third, contemporary, era focuses on professionalism as a quality or property of relationships and communication in microsystems and organizations.

Thinking about shared decision making evolved in a parallel and interdependent way. Early work focused on informed consent, a patient's legal right to receive information about the risks and benefits of treatment. The ethical clinician disclosed information. The relational concept of informed or shared decision making was introduced in the 1990s and was based upon evolving scholarship in ethics and communication. The ethical clinician was now expected to disclose information, ensure the patient understood the information, and share the decision-making process. However, Braddock and others found that most clinicians did not demonstrate the anticipated behaviors (Braddock *et al.* 1999; Gattellari *et al.* 2002). We offer two explanations for these findings. First, diagnostic disclosure became less burdensome because there was more that *could be done*. Prognostic disclosure remained – and remains – a challenge because it speaks to often unacknowledged limits to *what can be accomplished*. Second, prognoses are not objective in ways that diagnoses are: as a rule patients do not interpret diagnostic information to suit their worldviews. Prognostic understanding, on the other hand, may reflect what the patient has

heard and how they make sense of the information (Zier *et al.* 2012).

Furthermore, several qualitative studies strongly suggest that patients' experiences with decision making differ from expectations based upon ethical principles (McKneally and Martin 2000; Schildmann *et al.* 2013). Patients often do not perceive a choice and they accept the risks of treatment as inevitable costs of recovery. As well, the decisions around treatment involve questions of where, and by whom, rather than whether or not treatment is desired. In addition, some of the ways in which patients develop trust in physicians (referral process, reputation, and cultural expectations that cancer is treatable) are independent of a specific clinician and patient. Finally, patients may develop preferences for chemotherapy based upon a desire to maintain hope, live in the moment, or avoid the distress of waiting for additional treatment (Zimmermann *et al.* 2011; Buiting *et al.* 2013).

Thus, we do not fully agree with Kaldjian that the goal of shared decision making is agreement or that disagreement is best approached by a discussion of healthcare ethics with the patient. We believe that two parties with differing interests and values can clarify their views and engage in a continuum of behaviors that conclude with a commitment to negotiate further, compromise, or impasse without needing to 'un-share' a decision (Holm 2010). The examples presented by Kaldjian do not include any discussion, exploration, or elicitation of a patient's explanatory model of disease and illness, a point which he goes at some length to include as an 'ideal state' of the doctor–patient relationship. Similar to professionalism, thinking beyond the role expectations or ethical ideals leads to thinking about real-time conversations between patients and clinicians *who share time and space*. This is shared decision making *in situ*, the good, the bad, and the ugly of clinical reality (Matthias *et al.* 2013).

We agree wholeheartedly, however, with Kaldjian 'that researchers and healthcare professionals ought to be more candid and careful about the beliefs and values that guide the process of shared decision making' (Kaldjian 2017: 83). Oncologists' values and beliefs shape and are shaped by what happens – or what is supposed to happen – at the end of life. For example, quality of care measures such as no chemotherapy within

14 days before death or hospice enrollment for greater than seven days may represent visions of social good as much as patients' perspectives (Earle *et al.* 2008; Teno *et al.* 2012). The missing ethical conversations, in our view, however, are between clinicians, researchers, and policy makers. Asking patients to focus on the ethical foundations of healthcare at the EOL seems an unfair and unrealistic request.

4. The promise and perils of goals-of-care conversations

In his discussion of goals-of-care conversations, Kaldjian asks a question that contains a troubling claim: 'How can transitions in goals of care be orchestrated over time during the course of a progressive illness, especially when the goal of living longer *needs to yield to the goal of comfort?*' (Kaldjian 2017: 89, emphasis added) First, we are not aware of empiric evidence demonstrating that goals-of-care conversations will facilitate shared decision making about the transition to EOL care, and there are data that suggest the contrary. For example, our study of advanced cancer patients' life and treatment goals demonstrated that patients perceive treatment goals as distinct from, and more important than, life goals. In addition, there was no evidence that goals influenced the decision to receive chemotherapy (Rand *et al.* 2016). A qualitative analysis of interviews for a subset of the patients (those who lived less than one year) revealed that their treatment goals were the means to achieve their life goals. Furthermore, sharing their life goals was motivated, in part, by their desire to be known by their oncologist (Cottingham *et al.* 2017). In support of these findings, a qualitative study of patients with advanced cancer identified that a principal motivation to receive chemotherapy was a means for patients to live in the moment, rather than a result of prognostic misunderstanding (Buiting *et al.* 2013). Finally, the increase both in aggressive treatments near the EOL and hospice enrollment over time (Unroe *et al.* 2011; Wright *et al.* 2014) suggests patients with terminal diseases maintain two reasonable and compatible goals: 'I do not want to die unless *it is absolutely unavoidable*' and 'When I die, I want to *die comfortably*'.

A more troubling concern, however, is whether goals-of-care conversations, as conceived by Kaldjian, are a morally valid form of persuasion. What does he mean when he states that the 'goal of living longer needs to yield to the goal of comfort'? Where does the sense of imperative come from? In what ways do the clinician's expectations create an expectation of the patient that is not consistent with their goals of care? The answer to the question has real-world implications. A recent qualitative study of palliative care specialists' goals-of-care conversations revealed that one strategy was to 'close off a goal' (Norton *et al.* 2013). How does this differ from 'morally invalid efforts to change a patient's mind'? We can imagine conversations designed to clarify how unrealistic a treatment goal might be or to create a shared and actionable alternative to treatment goals, but it is troubling to think we may inadvertently endorse unilaterally eliminating a goal. We believe the temptation resides in what Thomas Finucane identified as the clinician's desire to 'avoid the regrettable misapprehension where "Do everything you can, Doctor" in life becomes "Why did this have to drag on so long?" after death' (Finucane 1999). Goals-of-care conversations are promising but require more empiric evidence and a parallel enquiry into the ethics of how physicians can validly influence patients' goals of care.

5. Conclusion

Robert Frost's poem *The Road Not Taken* provides an important caution to clinicians, researchers, and policy makers interested in improving the quality of EOL care through communication interventions. The apparently big differences at the end of a serious and ultimately fatal illness – dying at home comfortably surrounded by friends rather than dying in the intensive care unit in pain and alone – may not be due to variables that were *recognizable* and *actionable* at the beginning. Healthcare – or more specifically the practice of medicine – serves a moral purpose. But it also serves a practical purpose. And political. And economic. And intellectual. And, finally, personal. If we are to move beyond healthcare based upon what is available toward healthcare 'that is advisable in light of a patient's more enduring beliefs, values, and goals,'

then clinicians, ethicists, and society at large will have to honestly discuss the ways in which biomedical ingenuity – and the increasingly profitable rewards of marginally effective treatments – influence the values of the purpose-oriented landscape and the timely transition to EOL care. This is the missing ethical dialogue.

What about goals-of-care conversations between patients and oncologists? Intuitively – and despite the cited evidence to the contrary – we agree with Kaldjian that “[d]ecisions about interventions and tests should emerge from, rather than lead to, discussions about goals of care” (Kaldjian 2017: 88). We must, however, critically evaluate goals-of-care conversations as dynamic two-way conversations in which mutual influence, of different types to be sure, comes into play. We must learn more about patients’ influence(s) on conversations with their oncologists, as well as about patterns of behavior that indicate deference, disagreement, ambiguity, and impasse around decision making. Otherwise, our intuitions – ethical and practical – may lead us astray. As with the evolution in professionalism from the philosophical (what is possible) and ethical (what ought to be done) to the practical (focusing on behaviors), we should better understand the impact of goals-of-care conversations during planning the transition to EOL care before investing in teaching and learning another theory that ought to work but may not.

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