In support of goals-of-care discussions in shared decision making – An extended response to the rejoinders

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I am indebted to my colleagues – Larry Cripe and Richard Frankel, Martin Richards, Peter Scalia and Glyn Elwyn, and Angus Clarke – for the time they have taken to pose questions and offer comments that challenge and support my essay on the relationship between goals of care, concepts of health, and shared decision making (Kaldjian 2017). I am also grateful for the opportunity to respond (at some length!) to many of the issues raised, some of which are conceptual, some empirical, and some practical. Because most of the concerns relate to goals of care and shared decision making, it is to aspects of these topics that I will devote most of my attention.

Defining goals-of-care discussions

Larry Cripe and Richard Frankel, and Martin Richards, raise questions about the meaning and merits of goals-of-care discussions, and these questions invite clarification. I would start by stating plainly that what I have in mind when I recommend goals-of-care discussions is, simply, speaking with patients about their health-related goals and then discussing how their goals do or do not relate to their treatment choices. The kinds of goals I have in mind include such things as cure, live longer, improve function, comfort, achieve life goals, and support for family (Kaldjian et al. 2009). These are practical goals that are meaningful for patients and professionals, and they can be discussed.

Having said this, I acknowledge that the literature indicates how the contents of goals-of-care discussions can be expected to include more than just goals of care. For instance, one guideline recommends that these conversations include prognostic information, decision-making preferences, goals, fears, views about function, views about suffering (trade-offs), and wishes about family involvement (Bernacki et al. 2014). Given such a broad range of interrelated concerns, it is likely that the content of goals-of-care discussions will vary considerably according to the disease condition vis-à-vis the characteristics of the patient, family, professional, and situation involved. Supporting this impression is the observation that for some physicians and patients goals-of-care conversations may actually be more about rapport building, symptom management, and emotional issues than about treatment decision making (Schulman-Green et al. 2018), and a recent review of the literature suggests a lack of consensus regarding the elements of goals-of-care discussions and how they should be operationalized (Myers et al. 2018). The diversity of content in goals-of-care conversations invites us to decide what is essential for them. I would join those who maintain that at their core, goals-of-care discussions should be dialogues between health professionals and patients/families that assist patients’ treatment decision making through addressing their desired health expectations (Stanek 2017) by informing patients about their diagnosis, prognosis,
and treatment options, and clarifying patients’ beliefs, values, goals, and priorities in light of that information (Schulman-Green et al. 2018).

Goals of care discussions and the conceptual grounds for justification

To address the question of why we should be supportive of goals-of-care discussions, I would begin by addressing a narrower issue raised by Cripe and Frankel when they state that my essay makes ‘the explicit claim that goals of care are a helpful and necessary means to resolve clinician–patient disagreement.’ While it is true that I suggest that goals of care can be helpful in this regard, I do not claim they are a necessary means to resolve patient–clinician disagreement. As stated in the conclusion of my essay (Kaldjian 2017: 93), I suggest that by ‘probing the beliefs and values that explain why patients and clinicians endorse the goals of care and concepts of health they favor, the dialogues that facilitate shared decision making can help reconcile misunderstandings and resolve disagreements.’ I then add that ‘even when resolution is not forthcoming […] the respect shown by giving reasons that explain professional judgments can help reassure patients that they and their concerns are being taken seriously in the process of decision making and that avenues to consensus are still being sought.’ Furthermore, I suggest that such a dialogue ‘benefits greatly from discussions of goals of care, because patients and clinicians will both be encouraged to think about the larger and more enduring purposes for which medical tests and treatments are being considered.’ As to the question of necessity, it is true that at the end of Section 4 (Kaldjian 2017: 89) I use the word ‘necessary,’ as follows: ‘Though challenges of goals-of-care discussions are many, when done well they are as helpful as they are necessary.’ The context here is not patient–clinician disagreement, though, but a lack of engagement of goals of care in shared decision making, generally speaking. By ‘necessary’ I mean to connote the conceptual interdependence between rationality, purposiveness, and goal-oriented decision making, because I would maintain that for a serious decision to be rational (in the sense of well-reasoned) it needs to have a purpose, or goal.

It is this conceptual rationale that motivates my essay and its effort to portray the purpose-oriented landscape of healthcare in which shared decision making and goals-of-care discussions do and ought to occur. The essay’s purpose is not to make empirical claims about how goals-of-care discussions should be operationalized, when conducted, or how strong or weak the evidence base for their effectiveness is. My emphasis on a conceptual rationale reflects an assumption about decision making that recognizes an interdependence between rationality, purposiveness, and goals. On such an account, to make a ‘good’ decision (of a serious sort) is to make a decision that has a purpose and thereby aims at a goal. Indeed, I take it as uncontroversial that all good decision making in medicine is by definition purposive, and therefore goal-oriented. And I should add that in offering the framework I describe, I do not mean to suggest a theory, but rather to draw attention to under-emphasized details of what exists in the tradition of practical wisdom (in life generally) and clinical judgment (in medicine specifically) (Kaldjian 2014). These traditions support the idea of goal-oriented reasoning in shared decision making to identify plans of care that align with patients’ beliefs and values in specific clinical situations.

Goals of care discussions and empirical evidence for effectiveness

Having made these clarifications, let me say that I appreciate the questions raised by Cripe and Frankel and by Richards regarding the potential for goals-of-care discussions to reconcile disagreements between patients and physicians. Is there evidence to support their effectiveness in such settings? Stepping back for a moment for a broader view, we might begin by acknowledging that investigators are interested in studying the implementation of goals-of-care discussions generally speaking, for example in geriatric palliative care (Hanson and Winzelberg 2013), where research has demonstrated improvements in end-of-life communication and some practical outcomes (Hanson et al. 2017). And another clinical setting where goals of care have received much attention is in pediatric oncology, where efforts to integrate palliative care involve: (1) establishing a
relationship by understanding the patient’s/family’s experience of illness, sharing information, and assessing needs; (2) negotiating decisions by providing prognostic information, establishing goals of care, and discussing treatment options; and (3) developing a mutually agreed-upon plan (Levine et al. 2016). The need for such engagement is apparent in the results of a study of parents of children with advanced cancer, in which parent–clinician consensus regarding prognosis and goals of care was generally poor, and parents tended to be more optimistic than clinicians about the specific goal of cure – all of which prompted the investigators to recommend ‘early, open, and honest conversations about prognosis, hopes, and expectations’ (Rosenberg et al. 2014). Such remarks would seem to suggest that goals of care discussions are well suited to situations that are ripe for disagreement. Along these lines, a review of available data in the setting of pediatric oncology suggests that goals-of-care conversations are believed to play a constructive role in the increased use of advance directives and hospice enrollment, and they are recommended as a means of transparent and empathic communication aimed at creating a framework for identifying patient-centered and family-centered goals that can guide difficult decision making (Snaman et al. 2018).

But whether discussions about goals of care do in fact resolve, or at least help resolve, patient–physician conflicts remains a valid question, one that might be challenging to answer neatly through empirical means. Successful research efforts would depend on careful methodologies attending to definitions of goals-of-care discussions, design of interventions, and the ability to discriminate between the effects of discussing goals of care (narrowly speaking) and the effects of other dimensions of decision making that are expected to be part of goals-of-care discussions, such as diagnosis, prognosis, likelihood of outcomes, and burdens of suffering.

Without denying the importance of gathering empirical data to test conceptual frameworks and communicative approaches, I believe the conceptual grounds to endorse discussions about goals of care are firm. And I think these grounds explain why goal-oriented reasoning is accepted as part of ethical reasoning (Kaldjian et al. 2005) and clinical reasoning (especially in end-of-life care) (Swetz and Kamal 2018), and why there is so much interest in empirical investigation in the use of goals-of-care discussions, as shown by the variety of empirical literature cited throughout this response.

Being realistic

I am grateful that Richards finds the conceptual framework of my essay interesting and provocative. I am also mindful that he finds it ‘rather abstract and apparently rather far from the more messy and varied social relationships, and structures, which may characterise doctor–patient encounters across our health services.’ I take this concern seriously, because ideas that lack clinical relevance are not fit for the practical world of healthcare. Based on a face validity that derives from conceptual reasoning (as noted above), as well as clinical experience and some emerging data, I am confident that goals-of-care discussions, when engaged with care and competence, are neither abstract nor detached from the untidy circumstances in which we and our patients live and reason. If this were not so, it would be puzzling and concerning to find them so highly and routinely recommended, and so capable of integration into the unfolding stories of our patients’ difficult lives (Nenner 2013). Goals-of-care discussions should be as comprehensible and relevant to our patients as their experiences are real and burdensome. This is why goals-of-care discussions should involve questions as basic as, ‘Given this situation, what’s most important to you?’ (Swetz and Kamal 2018). When answered straightforwardly, this kind of straightforward, open-ended question can lead to the discovery of information about patients’ health-related expectations that speak to specific desires they have about their activities of daily living, particular life goals, or concerns regarding what is best for their loved ones. These are not abstractions – they are practical and personal realities in our patients’ lives.

So I agree with Richards that the practical relevance of goals-of-care discussions should always be in view, and my deepest reason for doing so rests on an observation that is, I believe, as compelling as it is ancient: rational decision making about important things is always goal-oriented. When we do serious things well, we do them for a purpose.
When a physician asks a patient, ‘Can you tell me what is most important to you at this stage in your life, or at this time in your illness?’ she can expect to learn something important about her patient. We see this especially toward the end of life. For example, is it important for this patient to live in his home, as long as possible? Is it important for him to live to celebrate an important event in the life of a loved one, if possible? Is it important for him to be comfortable, even if sleepiness is a side effect? Is it important for him to be awake enough to have fellowship with loved ones, even if more pain must therefore be tolerated? The practical knowledge gained from such discussions helps clinicians develop individualized treatment plans that tailor treatments to goals and enhance the quality of biopsychosocial-spiritual care they seek to provide.

Transitions in care

Cripe and Frankel suggest there is little evidence that goals-of-care conversations affect end-of-life decision making, and state that they are unaware of empiric evidence demonstrating that goals-of-care conversations will facilitate shared decision making about the transition to EOL [end-of-life] care, and there are data that suggest the contrary. They also believe that ‘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.’

The question of empiric evidence related to goals-of-care discussions during transitions in care is important, and its answer appears to be emerging. Leading voices in palliative care believe there is evidence that goals-of-care discussions benefit patients in such settings (Back 2017), based on, for instance, a prospective study of over 300 patients with advanced cancer demonstrating that end-of-life discussions are associated with less aggressive medical care near death and earlier hospice referrals (Wright et al. 2008), and that patients are more likely to receive end-of-life care consistent with their treatment preferences when they have had the opportunity to discuss their treatment wishes with a physician (Mack et al. 2010). A small study of patients with advanced illness in the emergency department suggests that goals-of-care discussions by emergency department staff (primarily physicians), lasting on average ten minutes, are associated with a greater likelihood that a patient with advanced illness will be discharged to home hospice (Liberman et al. 2018). There are also data to suggest that understanding patients’ goals of care may help calibrate their willingness to accept the side effects of treatment for their underlying disease. As described in a study of patients with ovarian cancer, patients were sequentially less willing to accept treatment side effects as the goal of treatment shifted from cure, to remission, to stable disease (Frey et al. 2017). It should also be emphasized that the conceptual, experiential, and empirical warrants to support goals-of-care discussions are sufficiently robust to have inspired considerable efforts to operationalize these discussions in practical ways. Some of these approaches are general (Bekelman et al. 2017; Childers et al. 2017), and some are specific to particular clinical settings, such as heart failure (Dougherty et al. 2017), cancer (Back et al. 2008), or emergency surgery in older persons (Cooper et al. 2016).

Why transitions in care can be so difficult

Richards invites us to give further thought to the issue of transitions by asking why the question I pose in my essay, about the shift to comfort care (Kaldjian 2017: 89), is so daunting. Though I think Richards answers his own question quite nicely, this issue invites reflection, for the literature in palliative care indicates that goals-of-care discussions can indeed be very difficult for some patients, families, and physicians. Why? There may be various reasons: fears, anxieties, and obstacles, including discomfort related to suffering and death (Kelly et al. 2003); the technological imperative, by which physicians and patients are socialized to assume that if biotechnologies are available they should be used (Barger-Lux and Heaney 1986); challenges that patients and families face when struggling to understand medical technologies and their limitations (Back et al. 2010) or to accept a poor prognosis and reconcile differences within their families (You et al. 2017); challenges physicians face due to suboptimal communication skills and feelings of sadness, loss, and powerlessness as a
patient’s disease progresses (Back et al. 2008); or challenges specific to particular clinical contexts that involve initiating and completing treatment options (e.g., cancer) or experiencing a gradual progression of functional losses (e.g., lung disease) (Reinke et al. 2008).

Additional examples in the literature from different clinical contexts help us understand more clearly the challenges and opportunities we face when speaking with patients about transitions in goals of care. In oncology, the challenge may be particularly demanding when it becomes clear to the oncologist that disease-modifying anticancer therapy is no longer effective for a patient. These discussions can be difficult ‘because they provoke intense emotions from patients and families, and a sense of failure from oncologists’ (Back et al. 2008). Efforts to facilitate the transition from curative to palliative care therefore need to provide clear information and help patients as they are coping with loss and trying to sustain hope (Evans et al. 2006). Recognition of the challenges involved in the transition to palliative care has led to educational interventions aimed at training physicians to speak clearly and empathetically with patients about their goals, values, and concerns (Back et al. 2007). In caring for adolescent patients living with progressive, life-threatening illnesses, clinicians may find it extremely challenging to discuss prognosis, treatment options, and goals of care while trying to promote adolescents’ emerging autonomy and also respecting their parents’ wishes to protect their children from the emotional distress of hearing ‘bad news’. Even so, these conversations can have an important impact on how patients live the ending of their lives, and how they and their families (and clinicians) cope with anxiety, sadness, and anger. Experienced palliative care providers believe these discussions should be pursued so that shared assessments of goals and preferences can lead to better decision making and less suffering (Rosenberg et al. 2016).

As another example, a study of parents of children with advanced cancer found that when parents’ prognostic understanding is aligned with concrete treatment goals, parents experience lower levels of psychological distress, even when parents understand their child’s illness is incurable, suggesting that early integration of palliative care strategies that include goals-of-care discussions should be used to facilitate the alignment of parents’ prognostic understanding with concrete goals of care (Rosenberg et al. 2013). The need to attend to the process of making transitions in goals of care during the course of a patient’s illness has even led some authors to coin the term ‘regoaling’ (Hill et al. 2014). Speaking within the context of children with serious illnesses, these authors note how complex these processes can be for parents who may persist in their initial goal for their child (such as the goal of cure or living longer) despite receiving increasingly poor prognostic information. The authors note that such persistence may be the way some parents try to maintain hope and engagement in their child’s care, or it may be seen as the only alternative to the unbearable anxiety, depression, and despair that come with the thought of shifting to a goal of comfort that acknowledges it is no longer appropriate to expect a cure or remission.

These examples describe an extremely challenging terrain, and they call for thoughtful approaches to communication that attend to patients and families in the midst of their grieving and struggling. One such approach is the ‘REMAP’ framework for goals-of-care conversations, which involves (1) reframing, (2) expecting emotion, (3) mapping out patient goals, (4) aligning with patient goals, and (5) proposing a plan (Childers et al. 2017). Though this approach was developed in an end-of-life care context (advanced cancer), its contents should be considered for generalizability to all other serious decision-making contexts in which information needs to be understood, emotions engaged, values prioritized, goals identified, and directions taken.

Implementing goals-of-care discussions

The preceding discussion of empirical evidence and proposed approaches to goals-of-care discussions anticipates the question posed by Scalia and Elwyn about how shared decision making should be implemented. This is a central question that encourages the search for approaches that make sense in the real world of patient–physician interactions, a world burdened by constraints created by structures and processes of care (Sinsky et al. 2016) that may not easily provide the time and space human beings need for meaningful dialogue. When
such dialogue happens, it should help patients understand the information that is relevant to their decisions, which we can refer to as the dimensions of decision making: diagnosis, prognosis, goals of care, probabilities of outcomes and complications, and burdens of suffering (Kaldjian 2014: 19–29). When reading the work of Elwyn et al. (2012), I appreciate the orienting power communicated by the question that they suggest ought to be posed to patients: ‘What, from your point of view, matters most to you?’ Though the authors suggest this as a means to explore patient preferences, I would suggest that it is also a means of exploring patients’ goals of care by asking specifically about the purposes (goals, expectations, or hopes) that they are most desirous to achieve through the care they receive. Patients and professionals may use ‘preferences’ and ‘goals’ to talk about similar, if not the same, things. Though the exact word used is less important than the meaning communicated, I find it helpful to speak about preferences in relation to treatments, and goals in relation to the purposes those treatments serve. In this way, treatment preferences are the means, and goals of care are the (proximate) ends served by those means. In any case, the more physicians become familiar with practical approaches to talking with patients about complex and demanding decisions, the better.

To this end, we can be encouraged to see that data, such as those noted above, continue to emerge regarding the apparently helpful implementation of goals-of-care discussions. An extensive review of this topic (Cummings et al. 2017), focusing specifically on patients facing ‘clinical deterioration’, has confirmed such an impression. The authors’ conclusions include the observation that goals-of-care interventions often are associated with perceptions (solicited predominantly from professionals, rather than by patients or families) of a positive impact on working practices, including patient benefit, improved clarity, and time saved as a result of discussions and decisions occurring earlier in the course of illness.

The meaning and dynamic of shared decision making

I appreciate much of the interpretation offered by Scalia and Elwyn regarding my description of the relevance of concepts of health for shared decision making, yet I would prefer to suggest that goals of care (more than concepts of health) serve as the focal point for dialogues aimed at determining the purpose of a treatment plan and identifying the best means to achieve it. When there are disagreements about the advisability of a given treatment option, part of the first step in conversation would be to address goals of care, and if it turns out that there are also disagreements about goals, then it may be helpful to address underlying beliefs and values that are represented in concepts of health. In pursuing such dialogues, the physician should be communicating medical and ethical reasons, respecting the patient’s autonomy, and both physician and patient should be growing in their understanding of each other’s reasoning. The professional purpose of this dialogue is to seek a shared and empathic understanding of the patient’s reasons (and desires, fears, and hopes) in order to enhance the physician’s ability to work with the patient toward a shared decision.

The intention of this joint effort resonates nicely with the emphasis by Scalia and Elwyn on the inter-dependence of patients and physicians and their need for partnership, which recalls the reference in my essay to relational autonomy (Kaldjian 2017: 85). One might suggest that when this partnership is enacted with respectfulness and sensitivity, the vulnerability and uncertainty of patients (mentioned by Scalia and Elwyn) may be mitigated when physicians know enough about their patients to help them reason and choose in ways that illuminate the connections between a patient’s guiding beliefs and values, their goals, and the treatments most likely to achieve those goals. This is one of the ways that a physician can, as Scalia and Elwyn say, ‘help guide the patient to a decision.’

In response to Richards’s remarks, I would also like to clarify and thereby emphasize that the dynamic of shared decision making is bi-directional. This means that the momentum of intentionality flows not only from physician to patient, but also from patient to physician, as the contrasts between the four vignettes in my essay demonstrate. The prospect of patient-to-physician intentionality is especially true when experienced or internet-informed patients make specific requests of physicians that physicians may or may not be willing to accept. This bi-directionality of
shared decision making can be highlighted by the parallel possibilities of recommendations (made by physicians) and requests (made by patients). Either party can initiate and propose; either party can object and disagree. For this reason we can see that shared decision making is not only evidenced when physicians come up with treatment plans that, if accepted by patients, result in shared decisions. There ought always to be an awareness of this bi-directionality, even if the large majority of treatment plans are developed and proposed by physicians.

Shared decision making that ends in disagreement

When values and beliefs conflict, there is the possibility of disagreements that, as I suggest in my essay, can result in ‘un-shared’ decisions, ‘because they are met with dissatisfaction on one or both sides of the patient–clinician partnership’ (Kaldjian 2017: 86). Richards questions this suggestion, and does so in reaction to the essay’s illustration of a man with chronic osteomyelitis, maintaining that the idea of an ‘un-shared’ decision ‘does not well describe the social processes that may be involved.’ He offers a rationale that could explain why a patient with osteomyelitis might refuse a recommended amputation in the hopes that antibiotics alone might cure the infection. I certainly appreciate this suggestion and realize that the very brief vignette offered in the essay provided little to highlight the severity of illness that would justify multiple physicians recommending an urgent amputation. I agree that, in some cases, an assessment of the dimensions of decision making (diagnosis, prognosis, goals of care, probabilities, burdens of suffering) may well be very open to contrasting but still reasonable assessments regarding the question of antibiotics alone vs amputation.

But imagine another possible reading of this scenario, one that is intimated by the words ‘urgently needs’. Imagine there is consensus among four physicians caring for the patient (representing expertise in primary care, infectious diseases, orthopaedic surgery, and vascular surgery) who without hesitation conclude and communicate that, on the basis of available data and experience, treatment based on antibiotics alone will not eliminate the infection and, moreover, would pose an immediate threat to the patient’s life due to the risk of sepsis (from bacteria that have already developed some forms of antibiotic resistance) and death. Imagine that in this scenario the patient still refuses amputation, and his physicians disagree. Such disagreements sometimes occur, and because they involve deep disagreements, physicians may in fact say that they disagree with the patient’s decision even while they respect the patient’s freedom to make it.

Freedom and disagreements, and the aim of shared decision making

The purpose of dialogue with patients about their beliefs and values related to such disagreements is to probe the grounds of decision to gain a better understanding of patients’ goals of care, and sometimes of their concepts of health. Such probing can help physicians understand (as mentioned in the essay regarding this case vignette) that the disagreement

is arguably the result not only of competing goals of care (cure of infection and increased likelihood of survival vs preservation of a foot), but also of contrasting concepts of health (physical health through the absence of infection vs psychosocial health through the preservation of bodily integrity, self-image, and well-being). (Kaldjian 2017: 90)

And because patients’ foundational beliefs and values constitute the commitments that express their moral integrity, I not only agree with Richards’s suggestion that ‘doctors should not always assume they are the sole judges of where a patient’s best interests may lie’, but would go further: physicians should never so assume. For in such situations, we see how the value of freedom can be honored by respectfully accepting a patient’s disagreement. An ‘un-shared’ decision may be the most respectful possible outcome of a difficult decision-making process, because it preserves the moral integrity of the patient (by not attempting to coerce action) and the physician (by supporting the acceptance of the patient’s freedom without pretending to endorse the patient’s decision). These are the kinds of respectful engagements that can address the deep disagreements that may
emerge in clinical care, as Clarke also illustrates with examples from the settings of neonatology and genetic counseling.

In light of the possibility that sincere disagreements may lead to ‘un-shared’ decisions, it is important to address the comment by Cripe and Frankel that my essay makes ‘the implied claim that the goal of shared decision making is agreement’. I do not intend to suggest that agreement is or should be the goal of shared decision making. Rather, I endorse shared decision making as a communicative process oriented to the promotion of the patient’s health within a purpose-oriented landscape (that includes treatments, goals of care, concepts of health, and the beliefs and values they rest on), a process that may or may not result in agreement. As stated at the beginning of the essay’s conclusion (Kaldjian 2017: 93):

Shared decision making is a dynamic process that depends on clear dialogue that allows patients and clinicians to share a broad range of information not only about medical facts but also about the beliefs and values that interpret and prioritize those facts. This dialogical process works best when test and treatment options are placed within a purpose-oriented landscape that sets goals of care (rather than interventions) in the foreground, so that decision making has a sense of direction before too much focus is placed on consideration of one or more possible next steps in clinical action.

These remarks indicate that the purpose of shared decision making, as I understand it, is to promote the patient’s health. Agreement between patient and physician about treatments and goals may be (and often is) a means toward fulfilling this purpose, but agreement is not itself the purpose of shared decision making. The fact that disagreements occur despite admirable engagements in processes of shared decision making demonstrates that shared decision making as a successful process does not necessarily result in decisions that leave both patient and physician satisfied (in the sense that both agree that the decision made is in the patient’s best interests).

Understanding the nature and place of persuasion

Cripe and Frankel also raise questions about the possibility of persuasion in shared decision making. They write:

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 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?

To begin, it is important to note that in my essay I do not say that goals-of-care conversations are a morally valid form of persuasion. Rather, I say that when disagreements arise, after informing patients and making recommendations, the question then...
becomes ‘whether anything “stronger” than information and a recommendation is in order, and this brings us to the possibility of using persuasion in response to a well-informed patient who refuses to accept a clinician’s recommendation’ (Kaldjian 2017: 87). I explain that by ‘persuasion’ I do not mean manipulation or coercion, but rather candid, respectful, and compassionate efforts that allow a clinician to ‘lean into’ a patient’s deliberations by engaging the question of the patient’s best interests through an understanding of his or her beliefs and values as they relate to diagnosis, prognosis, goals of care, possible interventions, benefits, burdens, probabilities, and possibly even financial costs.

Where does the physician receive warrant (if not imperative) for this? From the physician’s assessment of the patient’s best interests (which includes the patient’s freedom to make what the physician might consider to be a poor choice), and from the realities of biology and biotechnology, as the physician understands them. In the setting of care toward the end of life, experienced physicians know that there comes a time in the trajectory of a disease process when a compassionate and honest physician has an obligation to explain, on the basis of pathophysiological data, that one or more previously reasonable goals of care are no longer realistic and cannot be recommended. Of course, prognostication is not perfect, and yes, there are plenty of so-called grey areas where modesty and caution in prediction are necessary. Even so, there comes a time when a physician needs to say that biotechnological interventions aimed at a cure are no longer reasonable (i.e., attempts to cure by means of such interventions would most likely be futile). There also comes a time when a physician has good reasons to recommend, and perhaps attempt persuasion toward, a care plan that is shifted toward comfort, when efforts to prolong life have very low probabilities of success and very high burdens of suffering. This is not a matter of ‘unilaterally eliminating a goal’ (as expressed by Cripe and Frankel). Rather, it is a matter of giving reasons related to the physician’s perception of the patient’s best interests, and doing so with transparency and compassion, with the aim of helping a patient or family understand reasoning that is situated in the context of the biopsychosocio-spiritual needs of the patient. These grounds for making recommendations and sometimes attempting to persuade are directly related to Clarke’s recognition that as part of the ‘asymmetry in the doctor–patient relationship’ patients should expect from physicians ‘the knowledge, skill and experience’ they lack.

Attributing different concepts of health to patients and physicians

Most of my preceding responses have focused on goals of care and shared decision making, but here I will briefly turn to concepts of health. Richards draws critical attention to my tendency, which I admit, to attribute the biostatistical concept of health to physicians and the well-being concept to patients. For instance, I suggest that: “By and large, clinicians do well to rely on the biostatistical concept of health to assess the problems patients bring to the clinical encounter in order to determine whether these problems are, and will be treated as, medical problems” (Kaldjian 2017: 91), and “when clinicians disagree with patients about what course of treatment is most appropriate, or what goal of care is most reasonable, it may be because a clinician is working with a biostatistical concept of health while a patient is working with one that prioritizes well-being” (Kaldjian 2017: 93). However, I would also note that I acknowledge that physicians ought to have a broader view of health that encompasses multiple dimensions that support the idea of health as well-being. After endorsing the importance of a multidimensional concept of health (in which the biological substrate of disease affects and is affected by psychological, behavioral, social, and spiritual dimensions), I suggest that a clinician does well to focus primarily on the biological and psychological dimensions, while (hopefully) remembering the interrelatedness of all four dimensions to keep in view a broader range of a patient’s needs (Kaldjian 2017: 90).

In general, I believe physicians are aware of the contrast between illness (as something subjective that the patient experiences) and disease (as something objective that the physician observes). This is not to suggest that patients do not recognize and respect diseases, or that physicians do not empathize and engage with the experience of their patients’ illnesses. Throughout my essay, my intention was not to stereotype physicians and patients,
but to make the modest but meaningful claim that if there are deeper sources of disagreement between patients and physicians related to contrasting concepts of health, it is plausible to believe that physicians (based on their heavily biomedical models of training) are more likely than patients to be guided by a biostatistical frame of reference rather than one framed by well-being, especially when life or limb are at risk.

The patient’s story

I will close my remarks with reference to the reminder, from Scalia and Elwyn, that shared decision making is a process that occurs over time and through multiple engagements that build on each other as they reveal more and more about a patient’s story. Thinking of shared decision making as a process of understanding a patient’s story is very helpful, and it harmonizes with the claim that we ought to understand the relevant beliefs and values that guide a patient’s decisions. The narratives our patients tell help us appreciate the complexity of their lives in linear time and appreciate how their beliefs, values, relationships, motivations, actions, and consequences are interwoven. When decisions are contextualized in this way, the process of shared decision making is seen not merely as a matter of applying clinical logic and soliciting patient preferences at one moment in time, but as an engagement with the more enduring meaning of a patient’s life as reflected by her history and sense of identity (Montgomery 2006: 49). This brings us nicely to Clarke’s summary remark, that ‘any proposed medical intervention must be – and is in fact – located within a narrative and therefore within a context that relates to the concept of human flourishing.’ When clinicians take steps to understand their patients’ goals of care or concepts of health, they will learn more about their patients’ lives. This learning will make them more able to ‘read’ their patients’ stories and understand the depth of what their patients need to contribute to the process of shared decision making.

References


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