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Adaptive Care Planning: A paradigm shift

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Abstract

A key challenge of implementing advance care planning lies in the fact that decisions made in advance require patients and their family members to imagine what their clinical picture will look like rather than knowing or experiencing the clinical circumstances as they unfold. Even more important is the acknowledgment of the unpredictability of a given clinical course. This type of situation requires adaptiveness and flexibility in decision-making that frequently occurs in the moment(s) triggered by changes in health state(s). We describe an alternative frameshifting approach called "Adaptive Care Planning (AdaptCP)," which features an evolving communication between physicians and patients/families with ongoing incorporation of the patient's/family's perspective. This process continues iteratively until each decision can be reached in a way that is both harmonious with the patient's/family's perspective and is consistent with medical treatment options that are actionable for the healthcare team. We include a table of tools drawn from the literature that can help clinicians when implementing AdaptCP.

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> I thought doctors should only provide information and let a patient's family decide.
> However, it's hard for them to decide…
>
> —Sixth-year medical student candidate for residency;
> personal statement (Japan)

INTRODUCTION

Advance care planning (ACP) has, as we know it in the United States, been practiced since the mid-1970s,[1] evolving out of the advance directive movement (1960s). Early in the movement, it became clear that an advance directive decision requires not only a written document but conversations between patients and their healthcare providers.[1] Thus, ACP conversations became the gold standard for making and documenting decisions in the form of written advance directives and later, POLST, MOLST, and other advance directive documents. These conversations were to be undertaken between the patient and doctor/clinician in advance of disease onset "to ensure goal-concordant care near the end of life for patients who lack decisional capacity."[2] ACP has been associated with positive psychological outcomes for patients and families.[3] Recently, it has been recognized that ACP can improve, as despite its intent, some experts in the field believe that ACP has failed to fulfill its promise of achieving goal-concordant care.[4–9]

A key challenge of implementing ACP conversations lies in the fact that decisions made in advance require patients and their family members to imagine what their clinical picture will look like rather than knowing or experiencing the clinical circumstances as they unfold. Even more important is the acknowledgment of the unpredictability of a given clinical course. This type of situation requires adaptiveness, and flexibility in decision-making that frequently occurs in the moment(s) triggered by changes in health state(s).[5,10] When ACP is overly focused on advance decision-making and directive completion, it locks us into a certain trajectory or mentality when interacting with the patient and family, when we instead need to employ an adaptive approach.

Heyland challenges the current approaches to and terminology of ACP, but also highlights the need to distinguish between serious illness decisions and end-of-life decisions.[11] Heyland notes that this distinction is necessary for two reasons: (1) patients/families often picture the end of life when engaging in ACP or completing advance directives not experiencing serious illness, and (2) that end-of-life decisions happen "under conditions of certainty," whereas serious illness decisions happen "under conditions of uncertainty." A recent paper by Auriemma et al. reiterates this perspective.[6] One can imagine the patient's or family's decisions regarding treatment choices would vary considerably depending on the degree of certainty of a given situation. An adaptive approach could eliminate the need to make a distinction between serious-illness and end-of-life decisions and possibly eliminate the dependence on ACP as currently conceived.[5]

Ariemma et al. note that sometimes the completion of the advance directive (AD) document can even be counterproductive to the process of ACP as it could encourage a "one and done" mentality that impedes ongoing revisitation and reflection as the clinical picture changes.[6] Often, the belief of the clinician is that the patient has an AD, and therefore they must be followed without assessing where the patient is in the current moment regarding their care or treatment. POLST-discordant care is equated with inappropriate care in many studies.[12] Our goal should be to treat the patient and not the document. Each decision is a fresh start, while building on any consistent decisions since the patient's diagnosis. Even if the document exists, we need to meet the patient where they are and treat the person and be flexible with where they exist at any given moment.

The concept of "Serious Illness Communication" (SIC) has emerged in recent years as an important new construct and paradigm shift that addresses the limitations of the traditional ACP approach. SIC describes skilled communication that offers support for patients with serious illness and their families, over time, with a focus on eliciting goals and values and, when appropriate, a medical recommendation. It is associated with reduced anxiety and depression.[13] SIC conversations ideally occur longitudinally over time, and they are not necessarily triggered by a medical crisis.[9] In this article, we propose the term "Adaptive Care Planning" as the overarching construct for SIC and other health-related conversations that are triggered by changes in medical conditions and the in-the-moment need for decision-making across the disease trajectory. We believe this concept is particularly important for persons living with very advanced age, multimorbidity, frailty, or dementia. For these patients, there is often no clear line at which they become "seriously ill," and medical decision-making challenges can be expected at numerous junctions over time.

Adaptive Care Planning

Herein, we propose an "Adaptive/responsive care planning (AdaptCP)" approach in which decision-making about treatment or the reassessment of one's values and desires occurs in response to events as they unfold over time (Figure 1).[5,10] How can we support a process of decision-making that occurs in response to a serious illness diagnosis or prognosis,[16] a test result or a change in clinical condition, or in the setting of advanced age/frailty, that allows patients to decide what is important in the moment or in the reasonable "near" future? This approach does not eliminate the need to name a surrogate decision-maker or engage in estate planning. Additionally, planning is about the process and not (necessarily) the outcome (treatment choices), that is, the outcome "belongs" to the patient (and family) or is for the patient (and family) to realize (Figures 2 and 3). AdaptCP speaks to the timing—"in the moment(s)"—and the process of decision-making that would lead to treatment decisions derived from the patient's needs, desires, values, culture, and spiritual beliefs.

AdaptCP provides a process and tools that could help clinicians master the nuance of decision-making with patients and families as the clinical picture evolves. It is not always clear what events would cause a family to recognize that the end is near.

> Sometimes a family member is unable to understand the idea of dying from dementia until they can see it for themselves in their loved ones. A hip pressure ulcer developed in a 90+ year-old woman with advanced dementia, who was

nonverbal and bedbound, despite excellent care. Her body was just shutting down. The geriatrician had been communicating extensively with the son for months before and then daily during the patient's hospitalization, but he continued to insist on hospitalization, debridement and IV antibiotics. She was discharged from the hospital to the care home only to aspirate the same day, and the son insisted on rehospitalization and intubation. Only when he saw her in an ICU bed and intubated did he decide to pursue a comfort care approach. She died that day when he was present for the extubation.

Phases of AdaptCP

The first step in this process involves having the provider or team ascertain the patient and family's perspective/understanding of the current situation (Figure 2). By coming into the situation with an open, inquiring, and nonjudgmental attitude, the provider can help to address, when necessary, any negative emotions, misunderstandings, or other difficult feelings that are often present and can interfere with open communication. Once these emotions are recognized and addressed by the providers, the likelihood is increased that future communications will be productive and collaborative. Many communication tools and curricula, such as VitalTalk/GeriTalk, Serious Illness Communication, the Four Habits, and SPIKES protocol, have been developed to assist clinicians in developing the skills necessary for this step (Tables 1 and S1).

The second step is to then provide medical information tailored to the patient's specific situation. This information should come in small, digestible pieces, with frequent pauses and checks for understanding or emotional responses on the part of patients and their family members. This may result in the provider needing to resume the first task of gauging the patient and family's perspective again. It is often helpful to look at the medical facts, side by side, together with the patient and/or family, trying to make sense of where things are to create a picture of the patient's current situation or condition, rather than delivering the information as a lecture. There is an abundance of guidance on delivering prognostic information, as noted in the table (and Table S1), however, the challenge usually is knowing when to stop talking and let the patient and family digest the information and make sense of it.

The third step is to work with the patient and family to identify possible options for care and to assist them in creating a plan of care consistent with their goals and values for that point in time that makes the most sense to them. Resources for developing this plan of care with patients and families are more limited, but several excellent tools exist (Tables 1 and S1: organized into a 3-step process demonstrated in Figure 2. Step 1 entails communication skills and tools to help the clinician elicit the patient and family's perspective; Step 2, prognostication tools to help the clinician convey the patient's current condition; and Step 3, palliative care skills to help craft the plan of care appropriate for the current situation [i.e., selecting the right puzzle pieces and fitting them into place]).

Each decision fits together with prior decisions based on goals and values to form the patient's and family's care experience, and pieces from patient and physician fit together to

provide an outcome. Lack of clarity can occur if the patient or physician is not receptive, making it more difficult to create the appropriately shaped piece to fit the situation.

Sometimes families make unexpected decisions despite years of careful support and communication. Lack of clarity can result in a breakdown of the process even after years of collaboration and with all the relevant documents in place.

> One such patient was a 90+ year old man with dementia for over eight years, severe behavioral issues including eloping, paranoia, and resistance to care that was complicated by comorbid congestive heart failure, hyponatremia and a prolonged QT interval, and a spouse who was afraid to make decisions for him despite his advancing dementia.

> Over time with close support and follow up, the decision making shifted to the children, the patient was successfully transitioned to a supervised care environment and enrolled in a pre-hospice transitional care program, anticipating his progression to end-stage dementia. He had multiple urinary tract infections managed in the care facility with close communication with the caregiver, family, and the geriatrics and pre-hospice teams. However, when dysphagia and aspiration developed a few months later, the family chose to have him hospitalized rather than transitioning to hospice care in the care facility. The geriatrician and hospice social worker called the family to check in and were surprised by an angry family member who was not yet ready to transition the patient to hospice care.

> The patient was cared for in the hospital and then transferred back to the care facility without hospice at the request of the family. This transition occurred despite the patient's inability to safely swallow during speech therapy evaluations. The patient stabilized in the care facility for a month or two and then another aspiration pneumonia developed. This time, the caregiver and the family asked for hospice.

Life experiences such as discrimination in various settings (business, health care) have a major impact on patient and family members' willingness to trust the medical system and engage in decision-making. Many people, especially marginalized groups, may enter these discussions with the fear that the clinician's agenda is to give less care (because these groups have traditionally received less care). Often unskilled conversations are very agenda-driven (not offering "the full menu" relevant for care to a patient who may not have had access to "the full menu" of medical care in the past due to societal inequities), rather than based on eliciting goals and values and then making a recommendation based on those goals and values. It takes exploring, supporting, reassuring, and trust-building to begin the conversation. A patient or family's reticence to engage emphasizes the need to hear the person's story. The iterative discussion needs to address the patient's fears that they may lose autonomy over the decision-making process. If the patient engages in this discussion, will they still be offered all the options that are relevant to their care? When combined with a family member's caregiver stress, grief, guilt, and religious expectations that weigh into the surrogate decision-making process for their loved one, the only solution may be to slow down, listen to the perspective of the patient and family, and find a compromise that fits the patient's situation.

An 80+ year old man had overcome great obstacles in his life to become a successful businessman with several very successful children. When it came to healthcare decisions, he couldn't imagine a time when he wouldn't have the ability to make decisions. In addition, he wanted to be offered every option for care. Unfortunately, dementia and agitation developed, and over the next several years, he made several moves across the country to be cared for by each of his children until caregiver burnout resulted, and he was moved to the next child's house. Finally, he was living with his last child, who had a demanding career and was unable to supervise him at home. He was found wandering naked from his youngest son's house and was hospitalized. He remained in the hospital for weeks while finances, guardianship, and other complications of his refusal to make any plans for his future were addressed. Before discharge to the care home, the geriatrician spoke to the son, now legal guardian for healthcare and finances, about code status, but the son replied, "We're not at that point yet, he needs everything." Aspiration pneumonia subsequently developed, and the patient was re-hospitalized. The patient was refusing to open his mouth for a bedside swallowing evaluation, so hospice care was recommended.

At this point, his son requested that medical discussions include the patient's granddaughter, who was a nurse. The granddaughter correctly summarized that in the patient's current condition, "comfort feeding was considered "no feeding." She then commented, "The family hasn't accepted that he is dying." "I can see that he is in the last few months of life, even with tube feeding, but my uncles and aunts don't see this. So, we need some time for them to see him and grieve and accept where he is at."

The family discussion resulted in the decision to initiate a trial of tube feeding, and if the patient pulled the tube, the family would feel like they hadn't "just given up on him." The patient was discharged to the care home and pulled out the feeding tube within days of his hospital discharge. His family flew to be at his bedside and decided upon hospice care.

The prospect of in the moment, AdaptCP, requires an openness and receptivity to the patient and family's experience at that moment and an ability to take the patient and family's perspective and weave the current medical facts into that perspective. This process continues iteratively until a decision can be reached in a way that is both harmonious with the patient and family's perspective and is consistent with the reality of the situation and actionable for the healthcare team.[28]

These cases demonstrate evolving perspectives of families in the decision-making process. It may be hard to achieve goals that had been articulated earlier in the disease course, when life-threatening or end-stage manifestations of the illness seemed abstract or far in the future. Checking in with the patient and family, being open to their evolving perspective at each point in time, and responding to new information, little by little with an eye on the overarching goal, even when that goal changes over time, seems to make more sense, and supports the caregiver.[5,8]

The solution requires a paradigm shift from ACP to Adapt CP. In the AdaptCP model, conversations happen iteratively over time, in the setting of serious health conditions, and decision-making occurs at key decisional points rather than exclusively at end of life. As described above, AdaptCP consists of three phases: (1) communication skills and tools to help the clinician elicit the patient and family's perspective, (2) use of prognostication tools to help the clinician convey the patient's current condition, and (3) crafting a plan of care appropriate for the current situation (i.e., selecting the right puzzle pieces on the figure and fitting them into place). It also includes being understanding and receptive to the changing emotional states of the family as the diagnosis and/or care plan progresses, as they often take over decision-making in the late stages. An abundance of guidance and resources already exist in the literature for clinicians to accomplish AdaptCP. We summarize in Tables 1 and S1 select sources of training, skills, and information into a practical reference to help implement AdaptCP in the context of serious illness and other conversations.

CONCLUSION

ACP can be challenging, given that patients are asked to imagine disease states during periods of relative health and then make decisions about the types of treatment they would prefer should a serious illness ensue. AdaptCP model is a frame-shifting alternative to customary approaches that allows for in-the-moment(s) decision-making to occur in response to serious illness allowing providers/clinicians to adapt to the situation. We need to continue our ability to communicate with families and patients in the quest for person-centered high-quality care.

AdaptCP involves three phases that include communication, prognostication, and palliative care skills to help craft the plan of care appropriate for the existing situation (i.e., selecting the right puzzle pieces on Figure 2 and fitting them into place). We include tools from the literature to help clinicians prepare for and navigate the three phases of AdaptCP. This framework helps the clinician consider an AdaptCP strategy that shifts and adjusts to the changing clinical picture. AdaptCP allows for more flexible, adaptive decision-making, avoiding the need for patients (and their families) to imagine the disease in advance of its occurrence and instead working with the reality of their present experience of the disease as it unfolds over time.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

ACKNOWLEDGMENTS

SPONSOR'S ROLE

There is no sponsor to report.

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Key points

- Advance care planning and medical decision-making should adapt as information and conditions change.

- We introduce a model called "Adaptive Care Planning" to help clinicians engage in effective decision-making and care planning with patients and families over time.

Why does this paper matter?

New tools and communication strategies are needed to meet the needs of patients living with complex illness and advanced age.
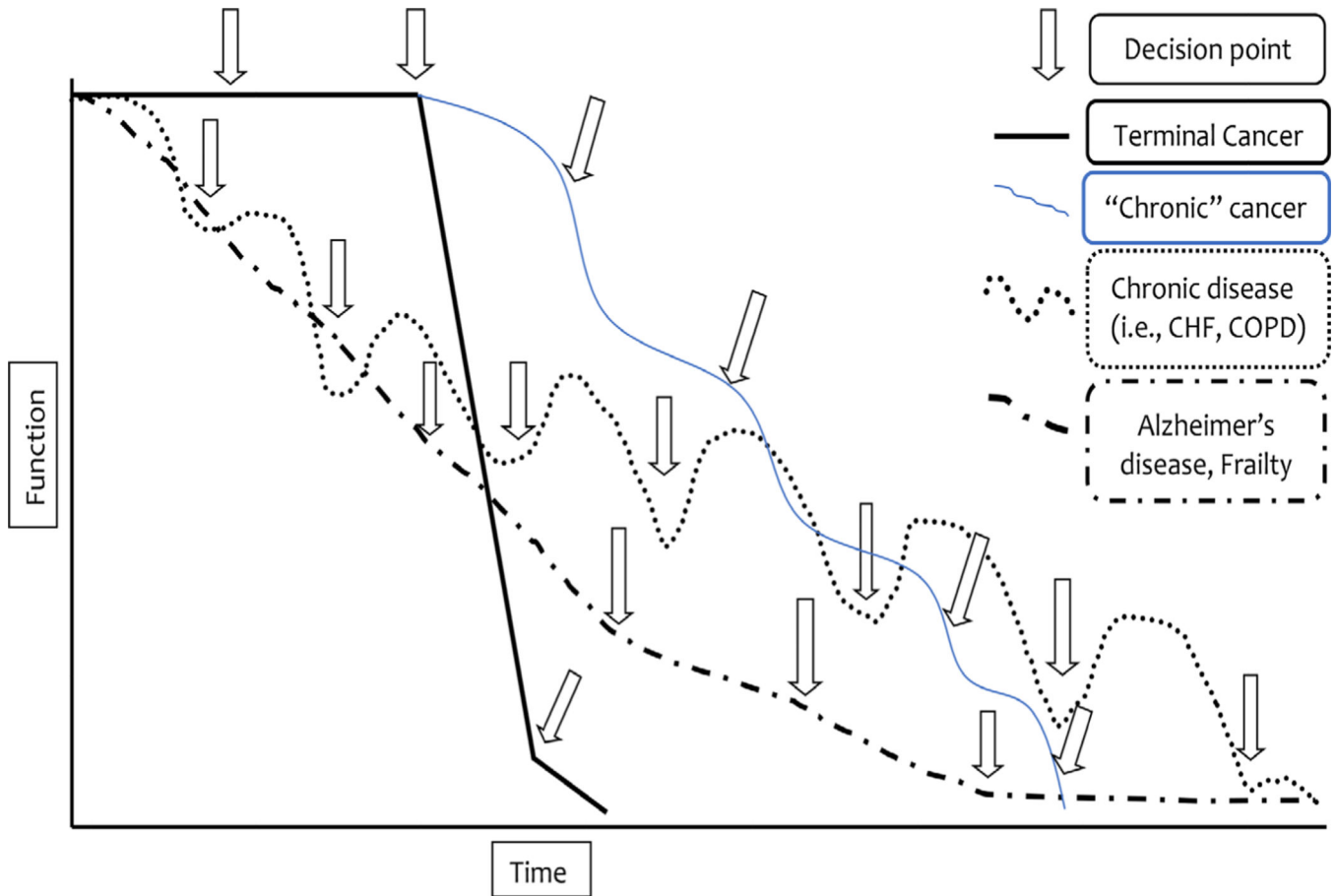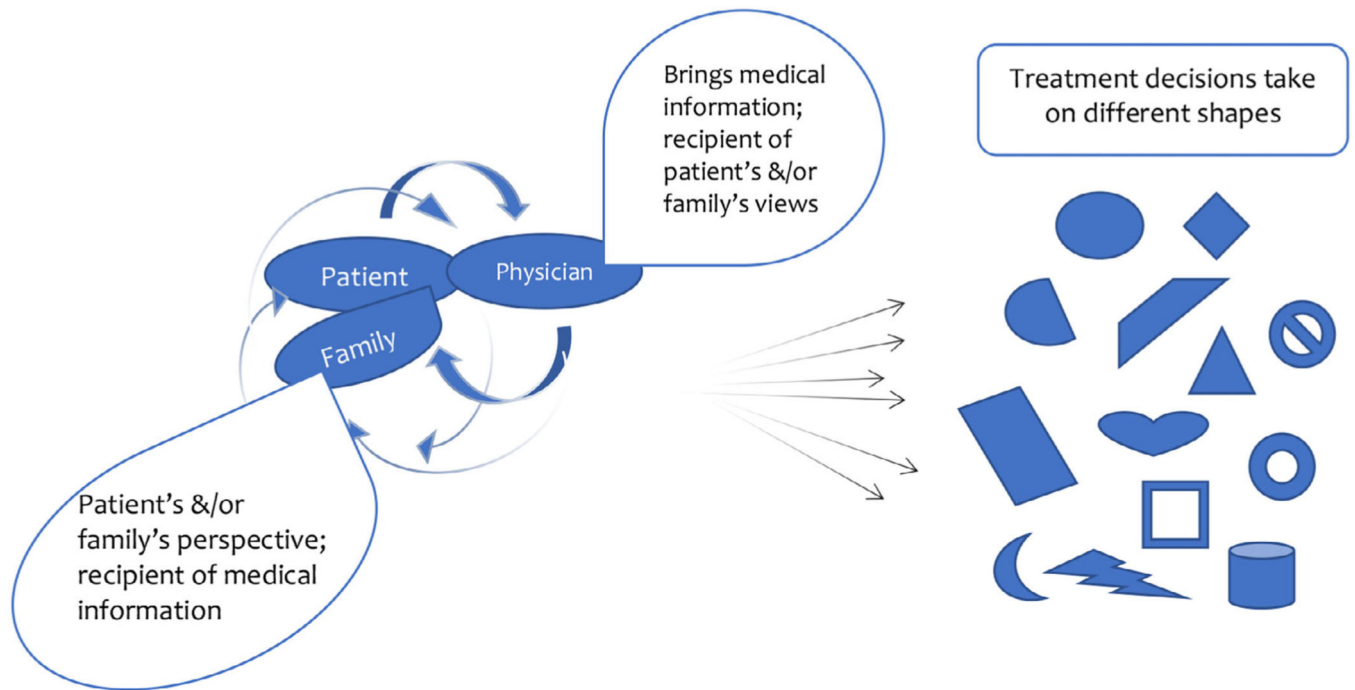
FIGURE 1.

Trajectories of different medical conditions and decision points for medical care discussions. In the classic trajectories,[14,15] with terminal cancer the change in function is abrupt and catastrophic, and the main decision points occur at the time of diagnosis and when the patient "takes to bed." Thus, advance care planning may be best conceptualized with the traditional simplistic terminal cancer trajectory in mind: the patient decides what kind of medical care they wish to receive when they reach the point of "taking to bed" and this decision then guides all subsequent care. However, in the more common chronic disease (e.g., chronic heart failure [CHF] or chronic obstructive pulmonary disease [COPD]), complex "chronic" cancer, and dementia- or frailty-type trajectories, there are many potential decision points for medical care discussions, highlighting the need for Adaptive Care Planning with multiple repeated discussions taking place over weeks, months, or even years.
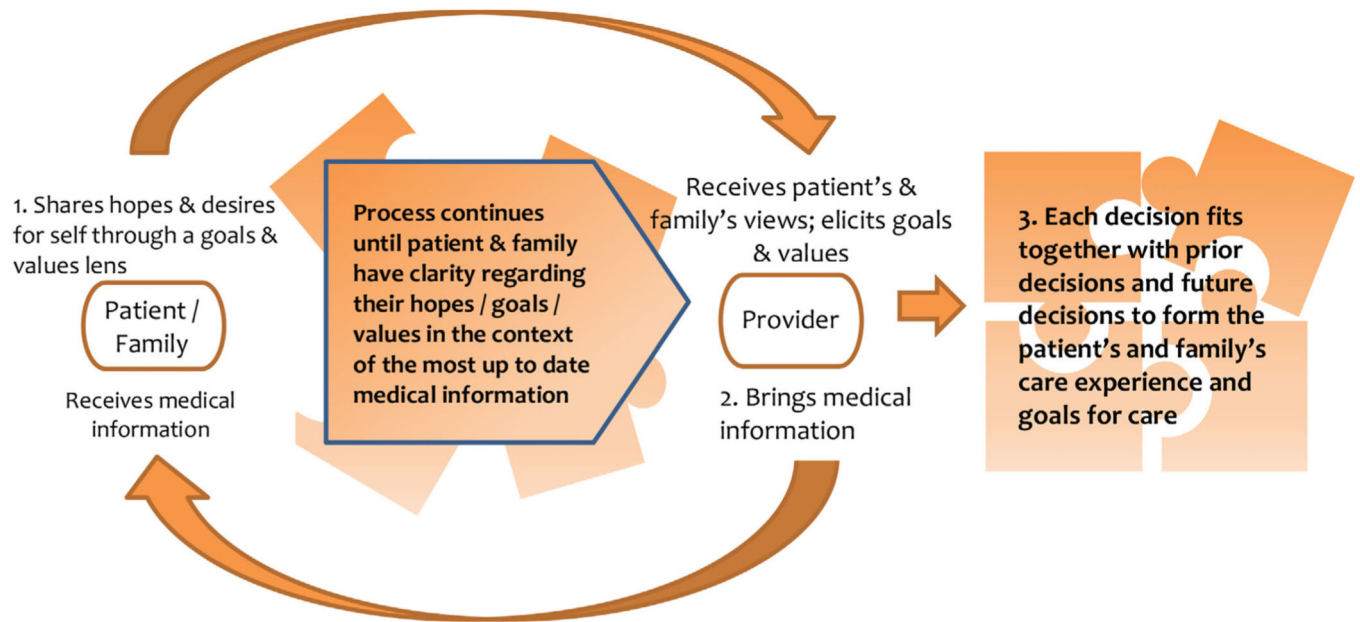
FIGURE 2.
Adaptive Care Planning (AdaptCP) processes include: (1) communication skills and tools to help the clinician elicit the patient and family's perspective, (2) prognostication tools to help the clinician convey the patient's current condition, and (3) palliative care skills to help craft the plan of care appropriate for the current situation (i.e., selecting the right puzzle pieces and fitting them into place).

FIGURE 3.

This figure illustrates the iterative communication and prognostication process shown in Figure 2 while demonstrating that the crafted plan of care may take on different shapes, for example, some patients may want full life-prolonging treatment, while another patient in a similar situation might opt for a natural death.

TABLE 1

Potential tools from the literature to facilitate Adaptive Care Planning.

Tool	Description
Step 1: Communication tools to elicit the patient's perspective	
Communication strategies	
The Four Habits Model[17]	4-step approach for patient encounter: 1. Invest in the beginning (establishing rapport efficiently) 2. Elicit the patient's perspective 3. Demonstrate empathy 4. Invest in the end
SPIKES protocol[18]	Stepwise process for conducting a meeting to share information about serious illness
SPIRES[19]	Stepwise communication framework to assist clinician in treatment decision-making for patients who may not do well with dialysis
Communication skills training programs	
Vital Talk[20,21]	Many communication tools and trainings useful in eliciting patient's/family's perspective: • Disclosing bad news • Defusing conflicts • Conducting family conference
GeriTalk[22]	Communication skills training for geriatrics and palliative medicine fellows
Center for the Advancement of Palliative Care (CAPC) communication skills training and modules[23]	Online self-directed courses on five different communication topics including: 1. Delivering serious news 2. Discussing prognosis 3. Clarifying goals of care 4. Conducting a family meeting 5. Advance care planning conversations
Step 2: Prognostication tools and metrics to convey the patient's current condition	
General prognosis tools	
E-Prognosis[24]	Website providing data on prognosis in various clinical situations Many include number of hospitalizations and Emergency Department visits in the past year
Surprise question	Would you be surprised if this patient died in 1 year
Condition-specific prognostication tools	
Frailty[25]	• Clinical Frailty Scale • In electronic medical record (EMR), weights can be graphed across time, the longer the better to give families a "long view"
Heart Failure[26]	• Stages—American Heart Association • The American Heart Association provided a helpful scientific statement with framework for decision-making
Step 3: Palliative care skills to craft the plan of care appropriate for the current situation	
Vital Talk[21]	Addressing goals of care and other resources
Advance serious illness preparations and planning (ASIPP)[7]	• Proposed alternative process of lining up values and preferences in serious illness discussion • Provides a flow diagram for decontextual planning: lining up values and preferences to help clarify decisions

Tool	Description
Education for Palliative and End-of-Life Care Project (EPEC)[27]	Standardized multicomponent curriculum offered in person and distance learning on essential clinical competencies of palliative and end-of-life care