

Accepted Manuscript



Towards a conceptual model of affective predictions in palliative care

Erin M. Ellis, PhD, MPH, Amber E. Barnato, MD, MPH, Gretchen B. Chapman, PhD, J. Nicholas Dionne-Odom, PhD, Jennifer S. Lerner, PhD, Ellen Peters, PhD, Wendy L. Nelson, PhD, MPH, Lynne Padgett, PhD, Jerry Suls, PhD, Rebecca A. Ferrer, PhD

PII: S0885-3924(19)30059-4

DOI: <https://doi.org/10.1016/j.jpainsymman.2019.02.008>

Reference: JPS 10037

To appear in: *Journal of Pain and Symptom Management*

Received Date: 4 September 2018

Revised Date: 24 January 2019

Accepted Date: 10 February 2019

Please cite this article as: Ellis EM, Barnato AE, Chapman GB, Dionne-Odom JN, Lerner JS, Peters E, Nelson WL, Padgett L, Suls J, Ferrer RA (2019). Towards a conceptual model of affective predictions in palliative care. *Journal of Pain and Symptom Management*, 57(6), 1151-1165. doi: <https://doi.org/10.1016/j.jpainsymman.2019.02.008>.

This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

Running title: AFFECTIVE PREDICTIONS IN PALLIATIVE CARE

Towards a conceptual model of affective predictions in palliative care

Erin M. Ellis, PhD, MPH (National Cancer Institute, Bethesda, MD, USA; erin.ellis@nih.gov)

Amber E. Barnato, MD, MPH (The Dartmouth Institute, Lebanon, NH, USA;
amber.barnato@dartmouth.edu)

Gretchen B. Chapman, PhD (Carnegie Mellon University, Pittsburgh, PA, USA;
gchapman@andrew.cmu.edu)

J. Nicholas Dionne-Odom, PhD (University of Alabama at Birmingham, Birmingham, AL, USA;
dionneod@uab.edu)

Jennifer S. Lerner, PhD (Harvard University, Cambridge, MA, USA; jennifer_lerner@hks.harvard.edu)

Ellen Peters, PhD (The Ohio State University, Columbus, Ohio, USA; peters.498@osu.edu)

Wendy L. Nelson, PhD, MPH (National Cancer Institute, Bethesda, MD, USA; nelsonw@mail.nih.gov)

Lynne Padgett, PhD (Washington D.C. Veteran's Affairs Medical Center, Washington, DC, USA;
lynne.padgett@va.gov)

Jerry Suls, PhD (National Cancer Institute, Bethesda, MD, USA; jerry.suls@nih.gov)

Rebecca A. Ferrer, PhD (National Cancer Institute, Bethesda, MD, USA; ferrerra@mail.nih.gov)

Corresponding author:

Erin M. Ellis

Erin.ellis@nih.gov

9609 Medical Center Drive

Rockville, MD 20850

Phone: (240) 276-5646

Fax: (240) 276-7883

Tables: 1

Figures: 0

References: 89

Word count: 6372

Abstract

Context: Being diagnosed with cancer often forces patients and families to make difficult medical decisions. How patients think they and others will feel in the future, termed *affective predictions*, may influence these decisions. These affective predictions are often biased, which may contribute to suboptimal care outcomes by influencing decisions related to palliative care and advance care planning.

Objectives: This paper aims to translate perspectives from the decision sciences to inform future research about when and how affective predictions may influence decisions about palliative care and advance care planning.

Methods: A systematic search of two databases to evaluate the extent to which affective predictions have been examined in the palliative care and advance care planning context yielded 35 relevant articles. Over half utilized qualitative methodologies ($n = 21$). Most studies were conducted in the United States ($n = 12$), Canada ($n = 7$) or European countries ($n = 10$). Study contexts included: EOL ($n = 10$), early treatment decisions ($n = 10$), pain and symptom management ($n = 7$), and patient-provider communication ($n = 6$). The affective processes of patients ($n = 20$), caregivers ($n = 16$), and/or providers ($n = 12$) were examined.

Results: Three features of the PC and ACP context may contribute to biased affective predictions: 1) early treatment decisions are made under heightened emotional states and with insufficient information; 2) palliative care decisions influence life domains beyond physical health; and 3) palliative care decisions involve multiple people.

Conclusion: Biases in affective predictions may serve as a barrier to optimal palliative care delivery. Predictions are complicated by intense emotions, inadequate prognostic information, involvement of many individuals, and cancer's effect on non-health life domains. Applying decision science frameworks may generate insights about affective predictions that can be harnessed to solve challenges associated with optimal delivery of palliative care.

Keywords: palliative care; advance care plans; affective predictions; affective forecasting; empathy gap

Towards a conceptual model of affective predictions in palliative care

Being diagnosed with a serious and possibly incurable cancer often places patients and their families in the position of making difficult high-stakes healthcare decisions without sufficient clinical knowledge and experience. Patients expect they or those close to them will experience feelings in connection with treatment options and consequent outcomes, referred to here as *affective predictions*, which may influence care-related decision making. However, evidence suggests individuals' affective predictions are often systematically biased [1-3]. In the advanced cancer context, decisions related to palliative care (PC) and advance care planning (ACP) may be particularly susceptible to affective prediction biases [4, 5].

PC is care that optimizes quality of life (QOL) and patient autonomy by managing symptoms and addressing patients' psychosocial needs [6]. ACP involves planning for future healthcare decisions that can be executed by others if a patient becomes too sick to make decisions herself [7]. PC and ACP are interrelated, as advance care plans often specify PC preferences, and ACP is one component of early PC. Recognizing the many benefits of PC for patients [8-12] and caregivers [10, 12, 13], clinical guidelines recommend early integration of PC into care [6]. However, PC and ACP remain underutilized or initiated too late [14-17]. This results in poor symptom management, greater difficulty coping with cancer, and EOL medical care that is not aligned with patients' goals and values. Therefore, more work is needed to understand and address the barriers to early PC uptake.

Biases in affective predictions are among several barriers that may impede delivery of early PC services (other barriers include workforce constraints [18], stigma [19], and misperceptions [19]). For example, early integration of PC often requires an oncologist referral, which is informed by the oncologist's assessments and predictions about both patients' future care goals and their affective reactions to a declining prognosis. Constructing an advance care plan that outlines PC preferences likewise requires patients and their loved ones to predict future values, goals, and affective reactions as the disease progresses.

This paper applies findings from the decision sciences to generate new insights about the role affective predictions play in deliberations about PC and ACP, thereby informing efforts to optimize PC delivery, increase goal-concordant care, and improve cancer outcomes. Our strategy was to integrate evidence about affective predictions from the PC and decision sciences literature and then to use the integrative review to identify several empirical questions for future research.

Affective predictions

Affective predictions have chiefly been examined in two foundational and related decision science research streams: affective forecasting [1] and projection bias (including the hot-cold empathy gap [2]) [3]. Affective forecasting research involves the estimates individuals make about their future feelings and how several biases influence these estimates [1, 20]. Although affective forecasts are often accurate about valence (i.e., positivity or negativity), they tend to overestimate the duration, intensity, and overall influence of an emotional experience, especially negative ones [1]. For example, individuals tend to overestimate how intensely and for how long a new disease diagnosis will influence their future happiness [21, 22]. Individuals also overestimate how long positive events, such as winning the lottery, will make them happy [21].

Several related biases contribute to this overprediction, including (but not limited to) focalism, impact bias, and immune neglect. *Focalism* involves a disproportionate focus on a single factor (when multiple factors are important), for example, overweighting factors expected to change (over those likely to remain the same), expected losses (over gains), and the differences between options (rather than their similarities). *Impact bias* is a form of focalism in which individuals disproportionately focus on

one event more than other events or factors that affect future happiness [20, 23, 24]. Focalism also may lead to *immune neglect* — underappreciation of personal coping resources to mitigate the experience of negative affect [21]. In the context of serious illness, these biases may lead to insufficient consideration of how the non-health aspects of life, including hobbies and relationships, may remain unaffected by illness and/or serve as support resources, which leads to overestimating future distress, fear, and sadness.

Projection biases involve a similar tendency to project the current state — including preferences, values, and affect — onto either a future state or onto other people [3]. When projection biases involve affective states, they contribute to hot-cold empathy gaps [2, 3]. The hot-cold empathy gap involves the difficulty predicting the experience of a “hot” visceral/somatic (e.g., pain, sexual arousal) or affective (e.g., fear, anger) state when not currently experiencing that intense state (i.e., when in a cold state that is less emotional or viscerally intense) [2, 25, 26]. Individuals in cold states underestimate the intensity of hot visceral or affective states and thus make inaccurate predictions about their future hot state preferences, decisions, and behavior. Conversely, individuals in hot states often mis-predict their future cold state selves.

The hot-cold empathy gap can be intrapersonal, such as when an individual who is not currently experiencing pain is unable to predict the intensity of a future pain experience. It can also be interpersonal — as when an individual who is not in pain cannot fully empathize with someone else experiencing pain. Research on the hot-cold empathy gap has found that individuals in cold states underestimate how intense and encompassing hot states can be, known as cold-to-hot empathy gaps [25-27]. Hot-to-cold empathy gaps may also be consequential, such as when patients and caregivers make medical decisions in response to distressing news that evokes fear, sadness, or anger. The decisions they make in these heightened emotional states may not align with their more stable cold state preferences and goals. Although most empathy gap research has involved the *intensity* of projected emotions (e.g., *how much* fear or pain), predictions about the *type* of emotion (e.g., fear vs. anger) may also be biased. For example, caregivers and patients may have affective reactions to an event, but fail to recognize they are experiencing different kinds of emotion.

The current study

Patients’ early affective predictions can influence the PC options available to them, including at EOL, through their effects on formal directives, such as advance care plans, and by shaping provider decision making and patient-provider conversations [28-30]. Ideally, advance care plans and early treatment decisions are revisited periodically to accommodate changes in disease status and care preferences, but in practice ACP often involves constructing written documents that are not adjusted to accommodate changes in patients’ goals [17, 31]. In addition, if a new cancer patient communicates to her oncologist a desire to pursue life-extension at all cost, her oncologist may be more likely to prescribe treatments that are off-protocol or have very low probability of efficacy and may be less likely to discuss PC or symptom management, even at EOL [32]. Thus, patients’ early affective predictions may have direct and indirect consequences for whether they receive PC in a timely manner and at EOL.

Given the potential of affective predictions to influence PC delivery, the current study reviewed the extant literature on the role of affective predictions in the PC context. We hypothesized this work would not necessarily utilize affective prediction terminology, so we integrated these findings with what is known about affective predictions in the decision sciences literature to outline several directions for future research. The PC context is complex and multidimensional, often involving patients, caregivers and health care professionals who may have competing and evolving goals. Thus, we hypothesized that affective predictions in this context would reflect greater complexity than what has traditionally been examined within the basic decision sciences literature.

Methods

Search strategy. PubMed and PsycNet (including PsycInfo and PsycArticles) databases were searched using the following terms: (affective forecast* OR "empathy gap" OR "hedonic adaptation" OR "anticipat* emotion*" OR "anticipat* affect" OR "impact bias" OR "affective misforecast*" OR "anticipat* regret" OR focalism OR "immune neglect") AND cancer AND ("palliative care" OR "advance directive" OR "advance care planning"). We supplemented this search strategy by scanning the reference sections of key review articles identified in the search. This search was current as of December 2018.

Inclusion criteria and coding. Two independent raters (EE, RF) evaluated the results of the search. Conference abstracts and articles in languages other than English were excluded. Articles were reviewed to determine whether they were relevant, semi-relevant, or not relevant to the review. Relevant and semi-relevant articles were reviewed and included in the Results. Articles were coded as relevant if they: 1) examined affective predictions (regardless of whether they were labeled or conceptualized as such); 2) were conducted in PC or ACP contexts; and 3) involved cancer patients, providers, or caregivers. Articles were coded as semi-relevant if they met criteria 2 and 3 and described an affective experience, but did not examine affective predictions specifically. Articles were deemed not relevant if they did not meet both criterion 2 and 3. Inter-rater reliability was high ($\kappa = .849$). Discrepancies largely involved articles coded as semi-relevant by one rater and relevant/not relevant by the other; they were resolved via discussion.

The search yielded 109 articles (PubMed: 107; PsycNet: 2; none overlapping between databases). Of these, 35 ($n = 30$ relevant; $n = 5$ semi-relevant) were included in the review and are noted with an asterisk in the References section. Articles were excluded for the following reasons: PC efficacy trials ($n = 21$); psychotherapy intervention trials that did not target affective predictions ($n = 4$); predictors of or screening for patient depression and anxiety ($n = 13$). An additional 36 articles were excluded in idiosyncratic categories, including: surrogate decision-making efficacy trials, scale development, or trainings to help providers deliver bad news.

Study characteristics

Studies were published between 1998 and 2018 and were conducted in the United States ($n = 12$), Canada ($n = 7$), European countries ($n = 10$), and elsewhere ($n = 6$). More than half of studies utilized qualitative methodologies ($n = 21$). Twelve involved EOL contexts, whereas ten pertained to decisions made earlier in treatment. The remaining studies examined predictions related to pain ($n = 5$) and symptom management ($n = 2$), or patient-provider communication ($n = 6$). Characteristics of included studies are summarized in Table 1.

Most articles described various factors that related to affective prediction but did not use that terminology or theoretical lens. To aim for more precision, we utilized terminology from the decision sciences where applicable (e.g., affective forecasting, empathy gap, anticipated emotions, focalism, projection bias). We organized our qualitative findings based on three features of the PC and ACP context that may contribute to bias in affective predictions: 1) early affective predictions are affected by intense emotions and insufficient information; 2) illness and PC decisions influence life domains beyond health; and 3) PC decisions involve multiple people. Below, we outline the evidence supporting each of these features.

Results

1) *Emotions and insufficient information bias early affective predictions*

Several review articles describe the intense emotions experienced by patients early in the treatment process. For example, a diagnosis of cancer elicits frustration, powerlessness, vulnerability, uncertainty, and shock [33]. Before they begin treatment, patients experience high levels of anxiety about the future and what to expect [34], as well as intense fear of severe pain and other disease-related symptoms [35]. These intense early emotions may lead some patients to make important treatment-related decisions that they later regret because they are unable to predict or anticipate that their intense emotions will subside, creating hot-cold empathy gaps [34]. Addressing patients' emotions directly [34, 36] and delaying discussions of treatment options until after emotions have subsided (i.e., providing a cooling off period) were noted as possible means of reducing early hot-cold empathy gaps [37].

Patients also report high levels of fear early in treatment [35], leading to overestimates of the severity of their future symptoms. For instance, cancer patients' four most feared side effects (nausea, vomiting, hair loss, and loss of appetite) prior to treatment were all much less feared, on average, once treatment started [38]. Many breast cancer patients also reported that their fears about future radiotherapy were much worse than their actual experiences [34]. Similarly, social (mis)perceptions about morphine may cause patients to overestimate likelihood of addiction and death, leading them to fear these medications and avoid optimal pain management [39, 40]. These findings are consistent with evidence that people overestimate the duration, intensity, and overall impact of negative events in their affective forecasts.

In addition to providing a cooling off period, one article suggested early discussions with a patient navigator may help correct misperceptions that contribute to patients' fears [34], and provide anticipatory guidance that could reduce biases in affective predictions [33]. For example, navigators may provide insight into the PC experiences of other patients with similar prognoses (e.g., did the other patient opt to receive PC services? How did they make her feel?), thereby helping patients anticipate their own affective reactions to PC. Early framing and initiation of PC services *in combination with* – and not as replacements for – other treatment modalities may also reduce the conflation of PC with hospice care and improve the accuracy of patients' predictions about their EOL care preferences [37].

Several of the articles identified in our review also referenced the evolving nature of patients' values, emotions, goals and identities throughout the progression of disease [33, 37, 38, 41, 42]. Most cancer patients perceive a relatively clear beginning, middle, and end to their disease progression [41], and note universally challenging transition periods, such as diagnosis, surgery and recovery, starting chemotherapy, managing symptoms, and recurrence [42]. Patients' priorities shift across these stages [41]. In addition to changes in goals and values that arise in response to changes in disease trajectory, individuals also change their preferences as they age and become sicker [43]. When possible, patients try to minimize feeling overwhelmed by managing these stages "one step at a time" [42], but this approach may exacerbate an "in-the-moment" focus that fails to consider the future and how personal goals may change. Thus, early affective predictions may insufficiently account for the extent to which one's goals and values will evolve over time.

Lastly, several articles described the poor prognostic understanding and/or unrealistic expectations of patients, which leads to misinformed predictions about the future, including whether a death is perceived as sudden [44]. Enrollment in clinical trials and vague provider-patient communication about prognosis may contribute to perceptions of prognostic uncertainty and overestimations (or false hope) about one's prognosis [45]. This may lead patients to pursue treatments with severe side effects and low probability of benefits based on inaccurate affective predictions and false hope.

In summary, patients' early treatment decisions may be overly influenced by their emotions at the time and fail to acknowledge that feelings may be less intense in the future (i.e., hot-cold empathy gap). Furthermore, intense early emotions, social misperceptions, poor prognostic understanding, and inability to anticipate how personal goals and values will evolve over the course of one's disease trajectory may contribute to biased affective predictions.

2) Impact of illness and PC decisions extend beyond physical health

The studies identified in our review describe many life domains beyond physical health that are affected by PC and ACP decisions (and a cancer diagnosis more broadly). Several studies underscore the importance of considering the "whole patient" when making treatment decisions [46-48] and correcting the perception that palliative and curative goals cannot be pursued concurrently [39, 40]. For example, Miccinesi (2017) suggests decisions related to pain management should be "proportional" so that symptoms are managed while minimizing patients' loss of personal values, pre-cancer identity, or autonomy (e.g., the ability to communicate) [46]. Patients' goals in various domains, such as spirituality, work, and relationships, are often equally or more important to them than their health goals when making treatment decisions [48, 49]. Patients report not wanting to be a burden to their loved ones and do not want to experience treatment side effects that influence their social relationships [39, 50, 51]. For example, patients may conceal their pain to protect loved ones [52], thereby undermining appropriate symptom management and resulting in worse outcomes [53]. Caregivers' identities and values are also complex, sometimes resulting in "role dissonance" or discrepancies in how different aspects of one's identity relate to the patient's care [47, 49]. Thus, patients are not the only individuals managing multiple life goals in their PC and ACP decision making.

Balancing several equally important goals and values across multiple life domains has implications for affective predictions. When goals conflict, ambivalent predictions or a complex blend of emotions may result, which cannot be fully captured by standard depression and QOL assessments [54]. One study aimed to minimize a disproportionate focus on one's illness (i.e., reduce focalism) through an intervention that addressed emotions, relationships, and living well while ill [49]. Such an approach may reduce biases in affective predictions by helping patients to clarify their underlying goals and values across the multiple life domains affected by their illness.

Affective predictions surrounding pain may be particularly complex. Patients make predictions about their future pain experiences based on deeply held beliefs and past experiences; they also report being very fearful about experiencing severe pain [35, 55]. However, pain is multidimensional, with unique physical, intensity-related, and affective dimensions (e.g., unpleasantness and distress) [35, 55]. Several studies suggest patients overestimate the affective component of pain in particular [35, 39, 55]. Indeed, Sela (2002) encourages providers to specifically address pain's affective dimension when discussing pain management [55].

In summary, our review suggests affective predictions in the context of PC and ACP can be complex and multidimensional because several life domains and potentially conflicting goals are affected by these care decisions. Predictions must also account for the multidimensional nature of pain and other affective experiences that arise in this context (e.g., simultaneously feeling hopeful and fearful).

3) PC and treatment decisions involve multiple people

Perhaps the most common theme across the studies in this review involves the role of multiple individuals in PC and ACP decision making. Although the majority of studies ($n = 20$) examined affective processes among patients, several studies also examined affective processes among caregivers ($n = 16$)

and/or providers ($n = 12$), reflecting the important role these individuals play in PC and ACP decisions. Indeed, many studies discussed the interrelated nature of the emotional experiences of patients, caregivers, and providers [50-52, 54, 56]. When making PC and ACP decisions, patients, caregivers, and providers frequently make predictions about others' current and future affective (e.g., fear) and visceral (e.g., pain) states. They then use those predictions to guide their own decisions and behavior. However, several studies noted disparities or differences between others' predictions and personal affective experience [39, 51-53, 57-61], reflecting interpersonal empathy gaps.

When these interpersonal affective predictions are biased, they have the potential to misinform treatment decisions. For patients, unrealistic predictions about caregivers' current and future affective experiences may prompt efforts to not burden loved ones near EOL [39, 50-52]. Patients may decide whether to accept a PC referral depending on how they expect it will burden their caregivers, and how they expect their caregivers will react emotionally. For example, patients consider their loved ones when making pain management decisions. Patients conceal their pain [52] and distress [50] from loved ones and may even engage in "altruistic opioid taking" in attempts to protect loved ones from witnessing their pain and the distress and fear it causes [39, 53]. These behaviors are based on expectations about how a caregiver will react emotionally to a patient's pain; thus, patients' mispredictions about their loved ones' reactions may misinform symptom management decisions.

Caregivers' affective predictions

Caregivers and surrogate decision makers also predict patients' feelings and goals so they can anticipate their needs and, when necessary, make decisions on their behalf [53, 62]. Often, caregivers make such decisions while experiencing intense emotions, which introduces the potential for hot-cold empathy gaps to influence their predictions. For example, the anticipatory grief period – a time of mourning an impending loss – can be even more distressing to caregivers than the actual grief after the loss [50, 56, 59, 61]. While the patient may be coming to terms with her cancer and finding peace as the disease progresses, caregivers often experience anger, fear, guilt, and frustration [50, 61]. In these intense emotional states, caregivers may overestimate patients' distress and symptom burden as a result of a hot-cold empathy gap [50, 53, 56, 61]. For example, incongruence between patients' and caregivers' reports of patients' somatic complaints usually reflect overpredictions by caregivers of patients' symptom burden and psychological distress [57, 61]. Conversely, caregivers in cold states also may underestimate the impact of patients' hot states, such as intense pain. According to patients' reports, caregivers and providers (who are not experiencing pain) seem unable to predict and infer the degree of pain experienced by patients [35, 39, 40].

The empathy gaps reflected in caregivers' affective predictions may influence whether patients receive PC when they can no longer make decisions for themselves and must rely on surrogates' decision making. Two studies suggest surrogate decision makers' current emotions are an important barrier to timely PC [42, 62]; patients whose caregivers were in denial or angry (versus had accepted the patient's diagnosis) had shorter lengths of stay in PC and hospice units [62].

Several studies identified the reluctance or failure to disclose personal feelings and poor communication as key causes of these empathy gaps [47, 50, 52, 63]. Open communication can be painful and force caregivers to acknowledge their loved one's imminent death [47]. Not surprisingly, these discussions tend to be infrequent and caregivers often hide their emotional distress when patients are present [52]. Patients even perceive and manage their pain differently depending on who is with them [39]. When potentially distressing topics are not discussed because of unrealistic predictions about others' emotional reactions, these predictions may not be corrected, empathy gaps persist, and caregivers remain unprepared emotionally and logistically for EOL [47].

Providers' affective predictions

Because oncologists are often the gatekeepers to early PC services, assuming the availability of specialty services, the empathy gaps they experience and their unrealistic affective predictions may be consequential for early integration of PC services. Several articles that examined patient-provider communication patterns identified evidence of empathy gaps and inadequate prognostic information as contributors to misalignment of treatment recommendations with patients' needs and goals.

Providers often make PC recommendations for patients who are in hot states (e.g., experiencing pain, stress, and distress) while they themselves are in cold states, introducing the potential for cold-to-hot empathy gaps [51, 57, 58, 60]. Our review suggests pain management may be particularly susceptible to empathy gaps. Patients perceive that pain is difficult to understand for those not experiencing it [39] and they perceive (often accurately) that their care teams do not believe their self-reported pain experiences [40]. Despite acknowledging the importance of pain management for patients, providers also poorly predict patients' symptoms, including pain [57]. They also overestimate their own knowledge about pain management, which may exacerbate the consequences of providers' poor predictions for patient care [58]. Thus, providers trying to manage patients' pain when they are not in pain themselves (and may never have had chronic pain) may experience empathy gaps that reduce the likelihood they will inquire about patients' pain or make appropriate treatment recommendations.

Empathy gaps may also arise when providers and patients differ in their emotional responses to changes in disease status. For instance, a provider's notion of hope usually centers on fixing the problem, whereas a patient's hope may not be tied to objective survival estimates. Patients may instead hope for the particular personal future that they envision for themselves, given their cancer [64]. On the other hand, parents of children with cancer often prefer more aggressive and radical treatment for their children, even at EOL, than do their children's providers [60]. This discrepancy in EOL care preferences may stem from several factors, including parents being overly optimistic about the prospect of curing their child's cancer, as well as patient-provider empathy gaps about how hope is conceptualized, maintained, and prioritized relative to other goals, such as symptom relief.

Providers' empathy was also cited as an essential component of good patient-provider relationships and medical care [64, 65], but the medical culture often promotes communication styles that are guarded, uninformative, and involve limited displays of feelings and emotions [64]. Nurses report experiencing a conflict between the emotional expressions they perceive as appropriate (e.g., smiling) and those they actually feel (e.g., extreme sadness) [66]. Providers often receive little formal training in how to communicate empathically [66] and they use distancing tactics for several reasons, including discomfort, fear of their own death, or perceptions that patients are unable to cope with uncertainty [65]. One study found that empathy erodes and distancing tactics increase over the course of providers' education and clinical practice [67]; however, in another study, an intervention to train physicians to be more empathic improved their ability to anticipate and respond to patients' emotions [63].

Patient-provider communication patterns may also indirectly exacerbate empathy gaps. To maintain patients' hope, providers may provide them patients with prognostic information that is incomplete or hard to comprehend, or they may hesitate to recommend PC services. Providers may also encourage enrollment in clinical trials, which sustains patients' uncertainty surrounding their prognosis and can make it difficult to accept death [45]. In combination, such behaviors may limit the patient's knowledge of and perceived need for PC services and exacerbate empathy gaps surrounding hope. Consequently, patients and caregivers may perceive an impending death to be sudden or unexpected, which increases the likelihood of inappropriate EOL care, and ultimately worsens bereavement among loved ones [44].

This review of the PC literature identified evidence that affective predictions and related biases are common in this context. Findings are consistent with and extend the evidence on affective predictions from the decision sciences, although few PC studies relied on formal theoretical frameworks or utilized affective prediction terminology to describe these processes. We identified three ways in which PC and ACP decision making introduce complexity into affective predictions.

First, early predictions are susceptible to the effects of intense emotions, insufficient or inaccurate information, and may be made without appropriate attention to possible changes in goals and values. Research from the decision sciences conducted in other health contexts (and thus, not a component of the formal review) supports these findings. Healthy individuals are often unable to predict what medical care they would want in future states of poor health [2, 3, 5, 22, 43, 68]. It is also difficult to account for the many ways in which personal affect, identity, goals, and values will change in response to declining health [29, 68-70]. For example, patients' and caregivers' depression can fluctuate widely over time, which influences their affective predictions [71, 72]. Individuals also engage in response shift and hedonic adaptation, processes that involve changing the reference group used to evaluate one's life, and also adapting to a new set of circumstances [73, 74]. Specifically, sick individuals may (unknowingly) shift their reference group from healthy family members or their former selves to other cancer patients, and change how they evaluate their lives as a result [73]. Similarly, hedonic adaptation is the process of becoming accustomed to one's new situation – usually far faster than predicted – thereby reducing its negative impact and shifting expectations about the future [74]. These processes, which are adaptive responses to adverse life events, may cause affective predictions to change, often in unexpected ways.¹

Our review identified prognostic uncertainty and insufficient prognostic information as possible sources of bias in early affective predictions. Rapid technological advances, such as immunotherapies [75], may contribute to increases in prognostic uncertainty and unrealistic expectations about the pace of future technological advancements. Unrealistic expectations about treatment efficacy or prognosis [76, 77] may misinform patients' affective predictions about how they will respond to changes in disease status, and may influence the treatment decisions they make in response. Overarching strategies for addressing these sources of bias include: emotion education programs for newly-diagnosed patients and their caregivers; patient narratives that describe the range of possible experiences in a way that is specifically designed to de-bias a forecast [78]; and improved delivery of prognostic information. Non-traditional forms of communication that evoke stronger affective reactions, such as narratives and videos/images, may be particularly useful.

The second factor that increases the complexity of affective predictions in the PC and ACP context stems from the many life domains, besides health, that are affected by a cancer diagnosis and PC decisions. Encouraging new patients to reflect on life domains beyond health may broaden their outlook and attenuate biases such as focalism, impact bias, and immune neglect [72, 79]. For instance, this process may help patients identify the many aspects of their lives that will remain unchanged despite their illness (e.g., spending time with family) or the many social and emotional resources that will help them cope. They may then be able to make treatment decisions with a more accurate estimation of how their illness will affect their future happiness and the happiness of their loved ones. This process of identifying core values and preferences may also help reconcile blended or ambivalent affective predictions, such as simultaneously feeling hopeful, fearful, grateful, and sad.

Some interventions, such as dignity therapy or having people create "bucket lists" already take this approach. Dying patients reflect on their lives and what matters most to them [80, 81], sometimes

¹ Response shift (and a similar phenomenon called scale recalibration) and hedonic adaptation also present methodological challenges for prospectively evaluating the accuracy of affective predictions because ratings scales may be interpreted differently before and after a life-changing event.

creating lists of their hopes for accomplishing or experiencing specific things during their lifetime [80, 82]. These strategies have been shown to improve EOL outcomes by facilitating treatment decisions that consider the whole patient. However, these interventions often occur as a component of PC at EOL [80], which may be too late for many patients to benefit from them. Identifying alternative means of providing these services earlier in care may optimize their potential to improve affective predictions.

A dignity therapy variant, where the caregiver is asked to talk about what the patient was like before getting sick, could help caregivers clarify their perceptions of patients' values and wishes [79], thereby preparing surrogate decision-makers for future decision making [28]. Asking caregivers to first describe what their own wishes would be, and then what they think are the patient's wishes may also help differentiate them and correct interpersonal empathy gaps [68].

The third factor that increases the complexity of affective predictions about PC and ACP involves the multiple individuals often involved in these decisions. Biased predictions about others' affect may actually reflect biases about how they themselves would feel in a similar situation [3, 83]. Then, these intrapersonal predictions are projected onto others via interpersonal empathy gaps. Anxiety and related emotions tend to increase egocentrism and impair perspective taking [84], thus exacerbating these processes. This may help explain the difficulties associated with strategies to improve surrogate decision makers' predictions. Several studies in non-cancer contexts suggest surrogate decision makers have great difficulty overcoming empathy gaps; even direct attempts to inform them of patients' wishes do not improve the accuracy of caregivers' predictions about a patient's EOL preferences [85-87]. A possible approach for reducing interpersonal empathy gaps may be to target surrogates' affective predictions about their own future care goals (e.g., through emotion education, narratives, and greater prognostic information). Also, given the important role caregivers play, the ACP process may benefit from greater involvement of caregivers and stronger emphasis on social relationships, whereas much of the emphasis has been on patient autonomy [28, 88]. This shift in framing may help both patients and caregivers communicate their values and emotions more openly, thereby improving the accuracy of interpersonal affective predictions.

This review suggests conceptualizing PC and ACP decision making with concepts derived from the decision sciences may facilitate interpretation of decisions and the ability to isolate targets for future interventions to improve PC delivery. Below, we outline several empirical questions (bolded) that leverage decision sciences theory to advance the study of affective predictions in PC contexts.

Future directions

Efforts to reduce bias in affective predictions may facilitate early interest in and initiation of PC services among some patients; for others, however, these efforts may result in care trajectories that center on life-sustaining treatments because this approach best aligns with their "fighting spirit" and is predicted to optimize happiness. Being able to predict these alternative outcomes may inform individualized interventions. **To this end, for whom and under what conditions will targeting affective predictions promote the uptake of PC services early in treatment and at EOL?**

Assessing the "accuracy" of affective predictions may be useful at times because an immediate comparison can be made at a single time point. For example, patient-caregiver empathy gaps could be measured by comparing the affective state of both the patient and caregiver, along with the prediction each individual makes about the other's affective state. Discrepancies between patients' [caregivers'] self-reported affect and caregivers' [patients'] predictions of the other person's affect are evidence of an empathy gap. For many PC and ACP decisions, however, using the accuracy of affective predictions as a metric for success poses challenges. For example, healthy individuals may hold stable care-related preferences prior to being diagnosed with an incurable illness, but because their care preferences change following a diagnosis and individuals have difficulty predicting such changes, these predictions

will be inaccurate [32]. Also, the gold standard for assessing intrapersonal accuracy should be comparison of the individual's predicted affective responses to the actual affective experience [89]. When these decisions are made near death, it may be unfeasible to make prospective (i.e., pre-post) comparisons. Feelings also evolve over time, sometimes in unpredictable and cyclical ways. **Therefore, what are the appropriate time points to assess pre-post affective reactions and how can they be prospectively identified?** There may also be instances where unrealistic affective predictions have beneficial effects on coping and adjustment, so promoting accuracy may not always be advantageous. **Thus, under what conditions may unrealistic affective predictions be adaptive?**

Other common measures of decisional satisfaction, regret, and certainty may also be challenging to apply in this context. For example, the amount of regret a patient or caregiver feels may change over the illness and life trajectory. It may also differ across patients and caregivers and depend on whether the patient/caregiver is focusing on herself or other involved individual(s) when considering the decision's effects. In fact, experiencing regret following a decision does not necessarily make the choice or the affective prediction that informed it erroneous. **Thus, which decisional processes or outcomes are useful indicators of decision quality, and which stakeholders are most important for which outcomes?**

Perhaps most challenging for evaluating affective predictions about PC delivery at EOL is the difficulty of identifying a universal means of evaluating a decision as "good." For example, opinions about what constitutes a "good death" vary and are highly personal, making it difficult to use "quality of death" as a metric (and assessing QOL immediately before death perhaps a more useful alternative). Moreover, these care decisions are often made in cases of clinical equipoise where there are poorly defined clinical guidelines and multiple objectively equivalent options. **To the extent that PC and ACP decisions should reflect goal-concordant care and patients' unique values, are there universal metrics for measuring success?**

The complexity of PC- and ACP-related affective predictions introduces several challenges for study and intervention. For instance, it may not always be adaptive or helpful for individuals to consider such a complex set of factors in their decisions. Less can be more when it focuses on the most critical decisional factors [90]. Patients also may be ill-equipped and/or unable to consider such complexities, regardless of whether it is objectively beneficial. **What level of complexity works for most patients, and what should be emphasized (e.g., predictions related to health and relationships)? Is it possible to predict patients' information needs so that it can be delivered in a tailored format?**

This complexity increases the difficulty of identifying objective criteria for judging whether outcomes and decisions are "good." For instance, a good choice for personal health may be a poor choice for finances, work, or marriage if it requires substantial investments of time and money. A patient's "good" decision to pursue aggressive care based on values of hope and determination may later be perceived as "not so good" if side effects compromise relationships. **In short, how can intervention efforts be tailored to accommodate the complex goals of individual patients?**

In light of these complexities, do patients need to emotionally prepare for all possible futures, or do they simply need to be open to the possibility of change and make adaptable plans accordingly? For instance, Halpern and Arnold (2012), Ditto et al. (2005), and others have argued that it may be unrealistic to expect individuals to accurately predict their future preferences in the PC and ACP context [5, 29, 91]. Surrogates may likewise be unable to predict patients' future preferences across all clinical possibilities [28]. Thus, other strategies that do not necessarily aim to correct the biases, but instead consider how to minimize their impact may be equally or more effective. For instance, check-points could be created where every patient's goals and values are reassessed and comprehensive information about available services is provided (e.g., in the context of revisiting an ACP). However, such an approach runs the risk of normalizing inaccurate or unrealistic predictions. **Could these approaches be implemented along with efforts to improve affective predictions? How can cancer patients prepare for**

the future, while also adjusting their plans as the situation evolves? How can affective predictions facilitate this process?

Conclusion

Biases in patients', caregivers', and providers' affective predictions may serve as a barrier to the optimal delivery of PC and ACP services, especially by influencing early treatment decisions that initiate hard-to-change care trajectories. Affective predictions in these contexts are complicated by intense emotions, inadequate prognostic information, the involvement of many individuals, and the impact that cancer has on life domains beyond health. Existing frameworks from the decision sciences, including affective forecasting, projection biases, and the hot-cold empathy gap, may provide a conceptual lens through which to examine affective predictions in the PC and ACP context. Applying and extending these decision science frameworks may generate insights about affective predictions that can be harnessed to solve challenges associated with the optimal delivery of PC.

Acknowledgements: The authors thank Chelsea Zabel for her contributions to the editing of this manuscript.

Funding: This research was supported in part by the National Science Foundation (SES-1559511). The sponsor of this research was not involved in its study concept or design, data analysis or interpretation, or in the preparation of this manuscript.

References

Note: Asterisk (*) denotes reference identified in literature review.

1. Wilson TD, Gilbert DT, *Affective Forecasting*, in *Advances in Experimental Social Psychology*. 2003, Academic Press. p. 345-411.
2. Loewenstein G. Hot-cold empathy gaps and medical decision making. *Health Psychol* 2005;24:S49.
3. Loewenstein G. Projection bias in medical decision making. *Med Decis Making* 2005;25:96-105.
4. Connors AF, Jr, Dawson NV, Desbiens NA, et al. A controlled trial to improve care for seriously ill hospitalized patients: The study to understand prognoses and preferences for outcomes and risks of treatments (support). *JAMA* 1995;274:1591-1598.
5. Halpern J, Arnold RM. Affective forecasting: an unrecognized challenge in making serious health decisions. *J Gen Intern Med* 2008;23:1708-12.
6. Ferrell BR, Temel JS, Temin S, Smith TJ. Integration of Palliative Care Into Standard Oncology Care: ASCO Clinical Practice Guideline Update Summary. *J Oncol Pract* 2016;13:119-121.
7. National Institute on Aging. *Advance Care Planning: Healthcare Directives*. 2018 January 15, 2018; Available from: <https://www.nia.nih.gov/health/advance-care-planning-healthcare-directives>.
8. Taylor DH, Bull J, Zhong X, Samsa G, Abernethy AP. The effect of palliative care on patient functioning. *J Palliat Med* 2013;16:1227-1231.
9. Ferrell B, Sun V, Hurria A, et al. Interdisciplinary Palliative Care for Patients With Lung Cancer. *J Pain Symptom Manage* 2015;50:758-767.
10. Singer AE, Goebel JR, Kim YS, et al. Populations and Interventions for Palliative and End-of-Life Care: A Systematic Review. *J Palliat Med* 2016;19:995-1008.
11. Zhang B, Wright AA, Huskamp HA, et al. Health care costs in the last week of life: Associations with end-of-life conversations. *Arch Intern Med* 2009;169:480-488.
12. Wright AA, Zhang B, Ray A, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA* 2008;300:1665-1673.
13. Casarett D, Johnson M, Smith D, Richardson D. The optimal delivery of palliative care: A national comparison of the outcomes of consultation teams vs inpatient units. *Arch Intern Med* 2011;171:649-655.
14. Jordhøy MS, Fayers P, Loge JH, Ahlner-Elmqvist M, Kaasa S. Quality of Life in Palliative Cancer Care: Results From a Cluster Randomized Trial. *J Clin Oncol* 2001;19:3884-3894.
15. Follwell M, Burman D, Le LW, et al. Phase II Study of an Outpatient Palliative Care Intervention in Patients With Metastatic Cancer. *J Clin Oncol* 2009;27:206-213.
16. Narang AK, Wright AA, Nicholas LH. Trends in advance care planning in patients with cancer: Results from a national longitudinal survey. *JAMA Oncology* 2015;
17. Tulsky JA. Improving quality of care for serious illness: Findings and recommendations of the institute of medicine report on dying in america. *JAMA Intern Med* 2015;175:840-841.
18. Lupu D, Quigley L, Mehfood N, Salsberg ES. The Growing Demand for Hospice and Palliative Medicine Physicians: Will the Supply Keep Up? *J Pain Symptom Manage*. 2018. 55:1216-1223.
19. Shen MJ, Wellman JD. Evidence of palliative care stigma: The role of negative stereotypes in preventing willingness to use palliative care. *Palliat Support Care*. 2018. 1-7.
20. Wilson TD, Gilbert DT. Affective forecasting: Knowing what to want. *Current Directions in Psychol Sci* 2005;14:131-134.

21. Gilbert DT, Pinel EC, Wilson TD, Blumberg SJ, Wheatley TP. Immune neglect: a source of durability bias in affective forecasting. *J Pers Soc Psychol* 1998;75:617.
22. Ubel PA, Loewenstein G, Schwarz N, Smith D. Misimagining the unimaginable: The disability paradox and health care decision making. *Health Psychol* 2005;24:S57-S62.
23. Dunn EW, Wilson TD, Gilbert DT. Location, Location, Location: The Misprediction of Satisfaction in Housing Lotteries. *Pers Soc Psychol Bull* 2003;29:1421-1432.
24. Smith D, Loewenstein G, Jepson C, et al. Mispredicting and misremembering: Patients with renal failure overestimate improvements in quality of life after a kidney transplant. *Health Psychol* 2008;27:653-658.
25. Ariely D, Loewenstein G. The heat of the moment: The effect of sexual arousal on sexual decision making. *J Behav Decis Mak* 2006;19:87-98.
26. Sayette MA, Loewenstein G, Griffin KM, Black JJ. Exploring the cold-to-hot empathy gap in smokers. *Psychol Sci* 2008;19:926-932.
27. Loewenstein GF. Out of control: Visceral influences on behavior. *Organ Behav Hum Decis Process* 1996;65:272-292.
28. Sudore RL, Fried TR. Redefining the "Planning" in Advance Care Planning: Preparing for End-of-Life Decision Making. *Ann Intern Med* 2010;153:256-261.
29. Ditto PH, Hawkins NA, Pizarro DA. Imagining the End of Life: On the Psychology of Advance Medical Decision Making. *Motiv Emot* 2005;29:475-496.
30. Halpern SD, Loewenstein G, Volpp KG, et al. Default options in advance directives influence how patients set goals for end-of-life care. *Health Aff* 2013;32:408-417.
31. Brinkman-Stoppelenburg A, Rietjens JA, van der Heide A. The effects of advance care planning on end-of-life care: a systematic review. *Pall Med* 2014;28:1000-1025.
32. Schenker Y, White DB, Arnold RM. What should be the goal of advance care planning? *JAMA Intern Med* 2014;174:1093-1094.
- * 33. Pedersen AE, Hack TF, McClement SE, Taylor-Brown J. An exploration of the patient navigator role: perspectives of younger women with breast cancer. *Oncol Nurs Forum*. 2014.
- * 34. Halkett GK, Kristjanson LJ, Lobb EA. 'If we get too close to your bones they'll go brittle': Women's initial fears about radiotherapy for early breast cancer. *Psycho-Oncology* 2008;17:877-884.
- * 35. Smith WB, Gracely RH, Safer MA. The meaning of pain: cancer patients' rating and recall of pain intensity and affect. *Pain*. 1998;78:123-129.
- * 36. Lobb E, Clayton J, Price M. Suffering, loss and grief in palliative care. *Aust Fam Physician* 2006;35:772.
- * 37. Saraiya B, Arnold R, Tulskey JA. Communication skills for discussing treatment options when chemotherapy has failed. *Cancer J Sci Am* 2010;16:521-523.
- * 38. Passik SD, Kirsh KL, Rosenfeld B, McDonald MV, Theobald DE. The changeable nature of patients' fears regarding chemotherapy: implications for palliative care. *J Pain Symptom Manage* 2001;21:113-120.
- * 39. Flemming K. The Use of Morphine to Treat Cancer-Related Pain: A Synthesis of Quantitative and Qualitative Research. *J Pain Symptom Manage* 2010;39:139-154.
- * 40. Reid CM, Gooberman-Hill R, Hanks GW. Opioid analgesics for cancer pain: symptom control for the living or comfort for the dying? A qualitative study to investigate the factors influencing the decision to accept morphine for pain caused by cancer. *Ann Oncol* 2008;19:44-48.
- * 41. Kendall M, Carduff E, Lloyd A, et al. Different experiences and goals in different advanced diseases: Comparing serial interviews with patients with cancer, organ failure, or frailty and their family and professional carers. *J Pain Symptom Manage* 2015;50:216-224.

- * 42. Schulman-Green D, Bradley EH, Nicholson Jr NR, et al. One step at a time: Self-management and transitions among women with ovarian cancer. in *Oncology nursing forum*. 2012. NIH Public Access.
- * 43. Stephens JD, Neal DS, Overman AA. Closing the empathy gap in college students' judgments of end-of-life tradeoffs. *International J Psychol* 2014;49:313-317.
- * 44. Hui D. Unexpected death in palliative care: what to expect when you are not expecting. *Curr Opin Support Palliat Care* 2015;9:369.
- * 45. Kars MC, Grypdonck MH, Beishuizen A, Meijer-van den Bergh EM, van Delden JJ. Factors influencing parental readiness to let their child with cancer die. *Pediatr Blood Cancer* 2010;54:1000-1008.
- * 46. Miccinesi G, Caraceni A, Maltoni M. Palliative sedation: ethical aspects. *Minerva Anestesiol* 2017;83:1317-1323.
- * 47. Sutherland N. The meaning of being in transition to end-of-life care for female partners of spouses with cancer. *Palliat Support Care* 2009;7:423-433.
- * 48. Tong E, Deckert A, Gani N, et al. The meaning of self-reported death anxiety in advanced cancer. *Pall Med* 2016;30:772-779.
- * 49. Miller DK, Chibnall JT, Videen SD, Duckro PN. Supportive-affective group experience for persons with life-threatening illness: reducing spiritual, psychological, and death-related distress in dying patients. *J Pall Med* 2005;8:333-343.
- * 50. Coelho A, Barbosa A. Family anticipatory grief: An integrative literature review. *Am J Hosp Palliat Care* 2016;34:774-785.
- * 51. Padgett LS, Ferrer RA. Palliative care in cancer: Enhancing our view with the science of emotion and decision making. *J Pall Med* 2015;18:479-479.
- * 52. Dev R, Coulson L, Del Fabbro E, et al. A Prospective Study of Family Conferences: Effects of Patient Presence on Emotional Expression and End-of-life Discussions. *J Pain Symptom Manage* 2013;46:536-545.
- * 53. Redinbaugh EM, Baum A, DeMoss C, Fello M, Arnold R. Factors Associated with the Accuracy of Family Caregiver Estimates of Patient Pain. *J Pain Symptom Manage* 2002;23:31-38.
- * 54. Ferrer RA, Padgett LS. Leveraging Affective Science to Maximize the Effectiveness of Palliative Care. *J Clin Oncol* 2015;33:4229-4230.
- * 55. Sela RA, Bruera E, Conner-spady B, Cumming C, Walker C. Sensory and affective dimensions of advanced cancer pain. *Psycho-Oncology* 2002;11:23-34.
- * 56. Chapman KJ, Pepler C. Coping, hope, and anticipatory grief in family members in palliative home care. *Cancer Nurs* 1998;21:226-234.
- * 57. Maguire P, Walsh S, Jeacock J, Kingston R. Physical and psychological needs of patients dying from colorectal cancer. *Pall Med* 1999;13:45-50.
- * 58. Kwon JH. Overcoming Barriers in Cancer Pain Management. *J Clin Oncol* 2014;32:1727-1733.
- * 59. Johansson ÅK, Grimby A. Anticipatory grief among close relatives of patients in hospice and palliative wards. *Am J Hosp Palliat Care* 2012;29:134-138.
- * 60. Tomlinson D, Bartels U, Gammon J, et al. Chemotherapy versus supportive care alone in pediatric palliative care for cancer: comparing the preferences of parents and health care professionals. *Can Med Assoc J* 2011;110392.
- * 61. Ullrich CK, Rodday AM, Bingen KM, et al. Three sides to a story: Child, parent, and nurse perspectives on the child's experience during hematopoietic stem cell transplantation. *Cancer* 2017;123:3159-3166.
- * 62. Kim SH, Hwang IC, Ko KD, et al. Association between the emotional status of family caregivers and length of stay in a palliative care unit: a retrospective study. *Palliat Support Care* 2015;13:1695-1700.

- * 63. Henselmans I, van Laarhoven HWM, de Haes H, et al. Training for medical oncologists on shared decision-making about palliative chemotherapy: A randomized controlled trial. *Oncologist* 2018;
- * 64. Richardson K, MacLeod R, Kent B. A Steinian approach to an empathic understanding of hope among patients and clinicians in the culture of palliative care. *J Adv Nurs* 2012;68:686-694.
- * 65. Kruijver IP, Kerkstra A, Bensing JM, van de Wiel HB. Nurse-patient communication in cancer care: a review of the literature. *Cancer Nurs* 2000;23:20-31.
- * 66. Mirlashari J, Warnock F, Jahanbani J. The experiences of undergraduate nursing students and self-reflective accounts of first clinical rotation in pediatric oncology. *J Nurs Educ Pract* 2017;25:22-28.
- * 67. Sinclair S, Beamer K, Hack TF, et al. Sympathy, empathy, and compassion: A grounded theory study of palliative care patients' understandings, experiences, and preferences. *Pall Med* 2017;31:437-447.
68. Halpern SD. Shaping end-of-life care: Behavioral economics and advance directives. in *Seminars in respiratory and critical care medicine*. 2012. Thieme Medical Publishers.
69. Winter L, Moss MS, Hoffman C. Affective forecasting and advance care planning: Anticipating quality of life in future health statuses. *J Health Psychol* 2009;14:447-456.
70. Gready RM, Ditto PH, Danks JH, et al. Actual and perceived stability of preferences for life-sustaining treatment. *J Clin Ethic* 2000;11:334-346.
71. Maciejewski PK, Prigerson HG. Emotional numbness modifies the effect of end-of-life discussions on end-of-life care. *J Pain Symptom Manage* 2013;45:841-847.
72. Chochinov HM, Tataryn D, Clinch JJ, Dudgeon D. Will to live in the terminally ill. *Lancet* 1999;354:816-819.
73. Ubel PA, Jankovic A, Smith D, Langa KM, Fagerlin A. What is perfect health to an 85-year-old?: Evidence for scale recalibration in subjective health ratings. *Med Care* 2005;43:1054-1057.
74. Frederick S, Loewenstein G. Hedonic Adaptation. *Well-being: The foundations of hedonic psychology* 1999;302-29.
75. Gotwals P, Cameron S, Cipolletta D, et al. Prospects for combining targeted and conventional cancer therapy with immunotherapy. *Nat Rev Cancer* 2017;17:286-301.
76. Hudson B, Zarifeh A, Young L, Wells JE. Patients' expectations of screening and preventive treatments. *Ann Fam Med* 2012;10:495-502.
77. Weinfurt KP, Castel LD, Li Y, et al. The correlation between patient characteristics and expectations of benefit from Phase I clinical trials. *Cancer* 2003;98:166-175.
78. Shaffer VA, Focella ES, Scherer LD, Zikmund-Fisher BJ. Debiasing affective forecasting errors with targeted, but not representative, experience narratives. *Patient Educ Couns* 2016;99:1611-1619.
79. Scheunemann LP, Arnold RM, White DB. The facilitated values history: Helping surrogates make authentic decisions for incapacitated patients with advanced illness. *Am J Respir Crit Care* 2012;186:480-486.
80. Chochinov HM, Hack T, Hassard T, et al. Dignity therapy: A novel psychotherapeutic intervention for patients near the end of life. *J Clin Oncol* 2005;23:5520-5525.
81. Chochinov HM, Kristjanson LJ, Breitbart W, et al. Effect of dignity therapy on distress and end-of-life experience in terminally ill patients: a randomised controlled trial. *Lancet Oncol* 2011;12:753-762.
82. Periyakoil VS, Neri E, Kraemer H. Common items on a bucket list. *J Pall Med* 2018;
83. Van Boven L, Loewenstein G. Social projection of transient drive states. *Pers Soc Psychol Bull* 2003;29:1159-1168.
84. Todd AR, Forstmann M, Burgmer P, Brooks AW, Galinsky AD. Anxious and egocentric: How specific emotions influence perspective taking. *J Exp Psychol Gen* 2015;144:374-391.

85. Fagerlin A, Ditto PH, Danks JH, Houts RM. Projection in surrogate decisions about life-sustaining medical treatments. *Health Psychol* 2001;20:166.
86. Shalowitz DI, Garrett-Mayer E, Wendler D. The accuracy of surrogate decision makers: A systematic review. *Arch Intern Med* 2006;166:493-497.
87. Ditto PH, Danks JH, Smucker WD, et al. Advance directives as acts of communication: A randomized controlled trial. *Arch Intern Med* 2001;161:421-430.
88. Singer PA, Martin DK, Lavery JV, et al. Reconceptualizing advance care planning from the patient's perspective. *Arch Intern Med* 1998;158:879-884.
89. Loewenstein G, Schkade D. Wouldn't it be nice? Predicting future feelings. in: Kahneman D, Diener E, Schwarz N, eds. *Wouldn't it be nice? Predicting future feelings*. Russell Sage Foundation Press: New York, NY, 1999:85-103.
90. Peters E, Klein W, Kaufman A, Meilleur L, Dixon A. More is not always better: Intuitions about effective public policy can lead to unintended consequences. *Soc Issues Policy Rev* 2013;7:114-148.
91. Fagerlin A, Schneider CE. Enough: The failure of the living will. *Hastings Cent Rep* 2004;34:30-42.

Table 1

Summary of articles identified in systematic review

Ref #	First Author (year)	Methodology	Context	Population			Affective Processes & Biases	Relevant Findings
				P	HP	C		
56	Chapman (1998)	Cross-sectional survey	EOL			X	Hope; anticipatory grief; death anxiety; empathy gaps	Gender, age, education, and coping strategies influence anticipated emotions. Anticipated emotions change over time, may differ within families, and depend on setting.
50	Coelho (2016)	Review	EOL			X	Anticipatory grief; ambivalence; changing predictions; empathy gaps	Anticipation of death fluctuates over time. Caregivers feel anger, fear, and guilt. Interpersonal emotion suppression and poor communication exacerbate empathy gaps.
52	Dev (2013)	Cross-sectional survey	Communication			X	Empathy gaps	Interpersonal empathy gaps caused by lack of communication and emotion expression in presence of patients. Discussions of prognosis and death are infrequent.
54	Ferrer (2015)	Commentary	Treatment decision making	X	X	X	Focalism; complex emotions	Depression and QOL measures do not fully capture the complex experiences of patients and their caregivers.
39	Flemming (2010)	Review	Pain	X		X	Affective forecasting; empathy gaps	Patients make affective forecasts based on “deep-seated” beliefs and values, which may not be accurate. Pain has an interpersonal component and is perceived as difficult to understand by those who have not suffered it.
34	Halkett (2008)	Cross-sectional survey	Treatment decision making	X			Anticipated affect	Uncertainty causes high anxiety early in treatment process. Fears about treatment were worse than actual experiences. Recommendation: address anticipated affect early.
63	Henselmans (2018)	RCT	Communication		X		Empathy gaps	Training improved oncologists’ skills related to anticipating and responding to patients' emotions.
44	Hui (2015)	Review	EOL	X		X	Anticipated affect	Poor prognostic understanding (or unrealistic expectations) leads to mis-informed predictions about the future, including whether a death is perceived as sudden.
59	Johansson (2012)	Cross-sectional survey	EOL			X	Anticipatory grief; anticipated affect; immune neglect; empathy gaps	Anticipatory grief period is distressing, partly because caregivers underestimate their ability to cope with loved ones’ death. Caregivers’ intense emotional states at EOL may lead them to poorly predict their future emotions and the patients’ emotions.

45	Kars (2010)	Cross-sectional survey	EOL		X		Immune neglect, focalism, changing predictions	Enrollment of pediatric cancer patients in clinical trials sustains uncertainty and impairs parental readiness for child's death.
41	Kendall (2015)	Interviews	Treatment decision making	X			Changing predictions	Progressive cancer has a predictable trajectory that is generally shared by patients, caregivers, and providers. Values and priorities evolve over the stages.
62	Kim (2015)	Interviews	EOL		X		Empathy gaps; anticipated affect	Family caregivers' emotions are important barriers to palliative care. Patients whose caregivers were in denial or angry spent less time in palliative care units. Family caregivers who feel obligated to stay hopeful may encourage more aggressive care.
65	Kruijver (2000)	Review	Communication		X		Empathy gaps	Empathic relationships between nurses and patients improves patient well-being. Distancing tactics are used by providers.
58	Kwon (2014)	Review	Pain		X		Empathy gaps	Discrepancies exist between physicians' perceptions of their knowledge of patients' pain and their actual knowledge.
36	Lobb (2006)	Commentary	Communication		X		Anticipated affect	Recommend providers discuss patients' expectations about the future (e.g., "Is there anything that is worrying you about the future in terms of managing your symptoms?")
57	Maguire (1999)	Interviews	Symptom management	X		X	Empathy gap	Providers poorly predicted patients' symptoms. Caregivers predicted some symptoms well (appetite loss, pain), but not others (breathlessness, pyrexia).
46	Miccinesi (2017)	Commentary	Treatment decision making		X		Focalism	Palliative sedation decisions must be proportional in that they manage symptoms while minimizing loss of personal values.
49	Miller (2005)	RCT	Symptom management	X			Focalism; complex emotions	Group intervention aimed at minimizing focalism by addressing: emotions; living well while ill; relationships; EOL planning.
66	Mirlashari (2017)	Journaling; interviews	Communication		X		Empathy gaps; emotion suppression	Nursing students experience negative emotions that cannot be communicated to patients and are not trained to do so.
51	Padgett (2015)	Commentary	Treatment decision making	X	X	X	Empathy gaps	"Hot-cold empathy gaps" occur intra-personally and interpersonally. Emotions are also socially transmitted.
38	Passik (2001)	Longitudinal survey	Treatment decision making	X			Anticipated affect	Early fears about side effects were all less frequently endorsed three to six months later.
33	Pedersen (2014)	Interviews	Treatment decision making	X			Anticipated affect; empathy gaps	Patient navigators should be assigned early in treatment to help patients cope with intense emotions and provide anticipatory

								guidance.
53	Redinbaugh (2002)	Cross-sectional survey	Pain	X	X	Empathy gaps		Greater disparity in pain ratings between patients and caregivers was associated with worse patient and caregiver outcomes.
40	Reid (2008)	Interviews	Pain	X		Anticipated affect (fear); empathy gaps		Patients fear opioids and associate them with death. Patients want their care team to believe their self-reported pain. Uncontrolled pain affects one's family.
64	Richardson (2012)	Commentary	Treatment decision making	X	X	Empathy gaps		One can empathize without direct experience (e.g., patients and providers may have different conceptualizations of hope).
37	Saraiya (2010)	Commentary	Treatment decision making	X	X	Anticipated affect; empathy gaps; changing predictions		Early treatment conversations are affect-laden, which impairs information processing. Delay discussing treatment decisions until after patient's emotions are addressed. Early framing of treatment modalities and interaction with palliative care is important. Goals and values evolve.
42	Schulman-Green (2012)	Interviews	Treatment decision making	X		Anticipated affect		Patients' "one step at a time" approach to managing their care is illusory, as multiple transitions occur simultaneously. Early palliative care could facilitate adjustment to transitions.
55	Sela (2002)	Cross-sectional survey	Pain	X		Empathy gaps; complex emotions		Physical and (multidimensional) affective dimensions of pain. Providers should alleviate fear when communicating about pain.
67	Sinclair (2017)	Interviews	Communication	X	X	Empathy gaps		Patients are perceptive to differences between sympathy and empathy/compassion and prefer the latter.
35	Smith (1998)	Cross-sectional survey	Pain	X		Anticipated pain; retrospective evaluations		Patients expect and fear severe pain. Pain intensity and pain affect are distinct. Pain recall was correlated with current pain experience.
43	Stephens (2014)	Cross-sectional survey	EOL	X		Affective forecasting; empathy gaps		Young (vs. older) adults are more likely to opt for pleasant death over longer lifespan in hypothetical EOL scenarios. Individuals fail to predict future care preferences when in good health.
47	Sutherland (2009)	Interviews	EOL		X	Anticipatory grief; changing predictions		In the meaning-making process, caregivers' values and identities change, are multidimensional, and ambivalent. Anticipatory grief and open communication can improve affective forecasts.
60	Tomlinson (2011)	Cross-sectional	EOL		X	X	Empathy gaps	Parents of pediatric cancer patients prefer more aggressive treatment for their children than providers do. Parents' hope for

		survey					a cure may override considerations of the child's quality of life.
48	Tong (2016)	Interviews	EOL		X	Impact bias; focalism; complex emotions; empathy gaps	Importance of multiple life domains (social responsibilities, work) influences adjustment at EOL.
61	Ullrich (2017)	Cross-sectional survey	EOL	X	X	Empathy gaps	Parents predict children are in greater distress than children self-report. Greater parental distress associated with higher ratings of their children's distress. May be bidirectional.

Notes

Populations: P = patient; HP = healthcare provider; C = caregiver

EOL = end-of-life