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PERSPECTIVES

Affective Forecasting: An Unrecognized Challenge in Making Serious Health Decisions

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Patients facing medical decisions that will impact quality of life make assumptions about how they will adjust emotionally to living with health declines and disability. Despite abundant research on decision-making, we have no direct research on how accurately patients envision their future well-being and how this influences their decisions. Outside medicine, psychological research on “affective forecasting” consistently shows that people poorly predict their future ability to adapt to adversity. This finding is important for medicine, since many serious health decisions hinge on quality-of-life judgments. We describe three specific mechanisms for affective forecasting errors that may influence health decisions: focalism, in which people focus more on what will change than on what will stay the same; immune neglect, in which they fail to envision how their own coping skills will lessen their unhappiness; and failure to predict adaptation, in which people fail to envision shifts in what they value. We discuss emotional and social factors that interact with these cognitive biases. We describe how caregivers can recognize these biases in the clinical setting and suggest interventions to help patients recognize and address affective forecasting errors.

KEY WORDS: decision-making; communication; patient preferences; doctor–patient relationship; quality of life.
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When facing medical decisions, patients make assumptions about how they will adjust emotionally to living with disabilities and declines in health. Yet we know little about how accurately patients predict their future well-being and the role of such predictions in their actual decisions.[1–3] Outside medicine, a burgeoning field of psychology—“affective forecasting”—consistently shows that people are poor predictors of their future well-being. Specifically, people overestimate the impact and duration of negative emotions in response to loss. People without a given disability rate their expected quality of life significantly lower than those actually living with that disability. Researchers have demonstrated this gap for paraplegia, visual impairment, heart disease, asthma, dialysis, or living with a colostomy.[1,4–6] The overarching conclusion is that people fail to envision their own capacities to adapt to declines in health.

Why should this concern physicians? Patients need to be able to form realistic beliefs about their future quality of life to make adequately informed decisions. Patients often choose among treatment options with similar impacts on mortality, but very different effects on their lives.[7–9] Patients need to form realistic beliefs about their future quality of life to make decisions ranging from whether to undergo screening to whether to pursue aggressive treatment at the end of life.[10–12] Beyond the clinic, the difficulties people have predicting their future well-being also appear to contribute to a wide range of faltering public health initiatives ranging from long-term disease prevention[13,14] to advance directives.[15]

Current models of shared medical decision-making presuppose a division of labor in which doctors are experts about the medical facts and patients supply values or preferences regarding outcomes.[16–18] This model fails to include the *beliefs* patients hold about their ability to adapt emotionally, which, along with their *values*, determine their decisions. In this article, we develop a framework to describe how cognitive, emotional and social biases influence patients’ beliefs about their future well-being. Much more clinical research is needed to illuminate how affective forecasting affects patients’ decision-making and to identify interventions to help patients make more informed choices.[19–24] As a start, we offer descriptions meant to help physicians identify affective forecasting biases that influence patients’ views of their future quality of life in various states of illness and disability.

We begin with three case examples.

CASES

Mr. Wishaw A highly independent police officer in his late fifties requires a second above-the-knee amputation as a result of type II diabetes mellitus. He was admitted to the hospital for dry gangrene in the affected leg. Despite antibiotics, the infection is progressing and the surgeons are worried that without surgery he may die. He understands the medical facts, yet refuses surgery because he can’t imagine his life using a wheelchair. He hates the idea of “not being able to run around

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with my grandchildren" and being so dependent on his wife. His wife, who loves him, is distraught, but says she will go along with whatever he decides.

Dr. Charania An intellectually gifted, independent and socially active 70-year-old university professor has a left middle cerebral artery stroke with hemiplegia and an expressive aphasia. With an intensive period of rehabilitation, she may be able to live independently. However, she is unlikely to move back to her home (too many stairs), nor is she likely to be able to return to teaching. The team communicates with her through a letter board and she shows that she understands her situation. They suggest that after rehabilitation she move into assisted living where she can receive more support. While not clinically depressed, she hates this idea, because she believes that even with rehabilitation, her deficits will prevent her from connecting intellectually or socially. She refuses to participate in rehabilitation and tells her children that she hopes God will take her soon because it is "her time."

Mr. Thompson A 67-year-old man receives a diagnosis of localized, low Gleason score prostate cancer. He urgently wants the cancer removed surgically, even though he understands that watchful waiting is considered a preferable strategy with fewer side effects. Mr. Thompson is unhappy about the possibility of facing impotence and urinary incontinence, but he and his wife feel that they can deal with it. He prefers the possibility of these side effects to feeling overwhelming anxiety about having "cancer inside," which he believes will continue unabated and destroy his peace of mind for the ongoing future. His doctor thinks that over time the incontinence will bother Mr. Thompson more than the anxiety, but he keeps quiet, assuming that the patient knows himself best.

All three of these patients are competent, show a high level of health literacy, and understand treatment risks and benefits. They can reason and make decisions based on their long-standing values. However, they are either not well-informed about, or not appreciating, an important element of their decision. The first two do not seem to know or even consider the fact that most people adapt to disabilities much better than able-bodied people predict that they will.[1,5,25] And Mr. Thompson does not seem to grasp accurately the relative impact of anxiety versus surgical side effects on his future quality of life.[8,26]

Their clinicians view these patients' decisions as tragic but believe they have nothing else to offer, having informed these patients about the medical facts. To further question them seems like meddling with personal values. Yet for these patients, it is not their *values*, but their *beliefs* that drive their decisions. Specifically, they believe that their current feelings of despair and anxiety will continue unabated into the future. For example, both Mr. Wishaw and Ms. Charania *want* to live and enjoy their lives, but they no longer *believe* that this is possible. Mr. Wishaw believes that he will be too disabled to play with and enjoy his grandchildren. Ms. Charania would opt to extend her life if she thought that she could maintain her social and intellectual engagement. Mr. Thompson values his quality of life highly, but believes that incontinence will be more tolerable than his anxiety.

Thus while their doctors conscientiously meet current standards for informing patients, these patients are actually not appreciating important aspects of their future quality of life. What should doctors and patients know about barriers to predicting quality of life?

PROBLEMS ENVISIONING FUTURE STATES

Cognitive Distortions in Affective Forecasting

Affective forecasting researchers have identified consistent gaps between healthy and ill populations' ratings of their well-being with disability or illness.[1,4–6,25,27–30] A recent review concluded that this "disability paradox" is not due to exaggeration by disabled individuals, but rather to the mispredictions of non-disabled individuals.[1] What specifically do people mispredict? Research shows that people usually predict the valence and specific emotion type accurately, but they mispredict the magnitude and duration of their emotional shifts from baseline. This occurs in three different ways: people focus more on what they will lose than on what will stay the same (focalism), they fail to envision how their own coping skills will lessen their unhappiness (immune neglect), and they fail to envision how they might develop new values (adaptation).[31–37]

Focalism Focalism refers to focusing narrowly on what will change in one's life while ignoring how much of what one enjoys daily can still be continued.[4,32,38] Thus, Mr. Wishaw imagines himself constantly depressed because he cannot walk or run, and he does not think about enjoyable experiences that he can still have, like meals with his grandchildren.

Focalism is the most easily recognizable problem in affective forecasting and appears straightforward to address—just ask Mr. Wishaw to list *all* the things he enjoys doing and then note that he will still be able to continue many of these. Yet while such defocusing exercises have worked in some non-medical situations,[38] they have not helped to reduce focalism about disabilities.[4,30] There also appear to be cultural differences in baseline focalism, which may give us important clues for designing interventions.[39]

Immune Neglect People generally fail to recognize the extent to which their defense, or coping, mechanisms will buffer them (provide "immunity") from emotional suffering.[33] Defense mechanisms are largely unconscious processes, ranging from developmentally early ways of shielding the self (which can be problematic in adult life)—such as denial and projection—to more mature coping processes, including rationalization, humor, intellectualization and compartmentalization.[40–43] Using such defense mechanisms truly helps people feel better,[44] yet we are largely unaware of these processes as they occur.[33,37]

Importantly, while some developmentally early defense mechanisms, like denial, are more powerful if kept unconscious and not challenged by reality, others need not be unconscious to work. Compartmentalization, humor, intellectualization, and sublimation are all coping mechanisms that we can consciously use. Further, recent research suggests that people who are more conscious of how they use coping mechanisms are also significantly better affective forecasters.[45] By asking patients about what helped them get through past difficult times, physicians can remind patients that they have many conscious tools for coping—for example, keeping busy, redefining options, or becoming more socially involved.[46] These interventions are already used to help patients envision coping with cancer.[47,48] Further, cognitive behavioral therapies (CBT) that help patients consciously experience and build their coping skills could be studied as ways of addressing immune neglect.[49–52]

Failure to Predict Genuine Adaptation Research consistently shows that people fail to *predict* adaptation,[30,44] despite findings suggesting that, over time, most people are highly adaptive to states of disability.[1,25] By adaptation we mean the process of forming new values, replacing lost sources of meaning with new ones.[53] For example, imagine that after her stroke, Dr. Charania, who had never listened to music, becomes an avid music lover. We need more research on how people adapt to particular medical problems over time, and we need to communicate these experiences to patients. For example, Mr. Thompson's physician could have let him know that research shows that anxiety lessens for most people over time, but that incontinence often causes an ongoing depreciation in quality of life.[8,26]

Recent research suggests that it is possible to help people better envision adaptation.[30] Support groups for cancer survivors have been shown to engender optimism and active coping.[54,55] Knowing people who have adapted to a similar disability or health condition seems to help patients envision better quality of life if living with a disability.[30] And even the stories of *virtual* others appear to be quite valuable, as evidenced by patients, avid use of Internet sites for sharing their experiences.[56] In clinics, interactive decision aids with narratives have been shown to help patients better understand treatment risks and benefits and experience less decisional conflict.[57–60] However, there are also ethical risks with using rich anecdotes to inform. A recent study showed that while 20% of participants said that they desired life-prolonging treatment if they had advanced Alzheimer's disease, after seeing a video of a patient and family's struggles, not one desired life-prolonging treatment.[61] Thus, the powerful impact of narratives might call for giving patients a time gap or debriefing between experiencing them and making their decisions.

Emotional and Social Influences on Affective Forecasting

In addition to the above cognitive biases (which occur even in calm states), emotional distress also influences how one appraises one's future prospects. Research shows that people make different projections about their future well-being when they are in positive versus negative emotional moods.[2,3,34] For example, fear can rivet attention on the most frightening aspects of a situation (worsening "focalism") or convince a person that a possible threat is inevitable.[53,62] Distress can block memories of better times, limiting one's ability to form more hopeful beliefs about the future.[63,64] Patients who are afraid and upset project these intense feelings onto the future,[65] and anxiety can undermine the reflectiveness needed to recognize such projections and address them.[65,66] For example, Mr. Thompson is distressed enough that it is difficult for him to imagine anything but his current anxiety continuing on into the future.

Physicians often need to address patients' emotional distress before they can address cognitive biases. Empathic listening, cognitive reframing,[49,51] gathering social supports, and encouraging peer support groups[54,67] are all effective ways to help alleviate patients' distress. However, when patients are upset, physicians sometimes respond in problematic ways, ranging from avoidance, to anger, to using stereotypes as a form of distancing.[68–70] And studies show that physicians' specific professional biases may lessen their ability to see patients' situations clearly, for example, when they are overly influenced by the memory of a rare bad outcome.[65,71] Therefore, physicians are likely to better address patients' emotional needs if they incorporate tools for reflective self-awareness into their practices.[72–74]

Finally, stigma forms a powerful barrier to envisioning adapting to disability. Stigmatizing images of illness and disability depict broken and unfulfilling lives.[75] Importantly, able-bodied people who know disabled people view living with disabilities more positively—perhaps because they gain realistic examples to imagine how they themselves could cope.[30] Healthcare professionals could make a difference by calling for measures to address the societal basis of exclusion and stigma, which would help make the real lives of disabled people more visible.[76]

IMPLICATIONS FOR FURTHER RESEARCH

We need research on the incidence of forecasting biases in patients, and on the impact of such biases on actual medical decisions. Much of the research on affective forecasting has taken place in experimental psychology or behavioral economics labs with college students. We currently have almost no longitudinal data showing how individual patients actually adapt emotionally compared to their predictions, or about how patients vary in their abilities to predict future well-being.[28,77,78] A crucial first step would be to establish empirical and clinical ways of identifying when decision-making is being disrupted by affective forecasting problems.

This research agenda also would benefit from crossing disciplinary boundaries, bringing together methods from social and cognitive psychology, behavioral economics, clinical research, and neuroscience. For example, clinical research shows that health state preferences change as patients experience serious health declines, suggesting the importance of longitudinal data.[79] An fMRI study might identify brain differences corresponding to these preference changes in illness-experienced subjects, and cognitive psychology methods might look at differences in patients' use of automatic versus deliberative processing depending on illness severity.

Finally, we need to study the impact of decisional supports on affective forecasting.[80–83] Research is needed on how such aids can incorporate forecasting interventions, such as helping people recall previous coping[30] and providing narratives about how people respond differently to health challenges. Interestingly, patients, rather than clinicians, may lead the way in developing effective interventions, for example, through developing websites about coping with illness and disability.[56] Physicians who educate themselves and their patients about forecasting biases and stay abreast of the diverse ways that patients learn about living with illness and disability will be better equipped to help patients make informed decisions.

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