Predicting preferences: a neglected aspect of shared decision-making

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Abstract

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In recent years, shared decision-making between patients and doctors regarding choice of treatment has become an issue of priority. Although patients' preferences lie at the core of the literature on shared decision-making, there has not been any attempt so far to link the concept of shared decision-making with the extensive behavioural literature on people's self-predictions of their future preferences. The aim of the present review is to provide this link. First, we summarize behavioural research that suggests that people mispredict their future preferences and feelings. Secondly, we provide the main psychological accounts for people's mispredictions. Thirdly, we suggest three main empirical questions for inclusion in a programme aimed at enriching our understanding of shared decision-making and improving the procedures used for putting it into practice.

Introduction

In recent years, clinicians and health-care experts have argued for what has been termed 'shared decision-making' between patients and doctors regarding choice of medical and surgical treatments.¹ The patient has been described as a 'key medical decision-maker',² who needs to be fully engaged in the care plan.^{3,4} In addition, patients who are involved in the decision-making process jointly with their clinicians have recently been described as potentially active contributors to the safety of the care provided to them.⁵

The cornerstone of shared decision-making is patient preferences. In this context, we define 'preference' in terms of the *positive or negative feelings and emotions* that patients associate with an illness and with the outcomes of the available treatments for it. Our definition is not in conflict with the definition of patient

preferences as positive or negative attitudes towards bundles of (disease or treatment) outcomes.⁶⁻⁹ In addition, our definition takes into account the fact that preferences may be *predicted* or *experienced*. Emotions that patients think that they will experience in the future as a result of a disease or its treatment define their predicted preferences. Symmetrically, emotions that patients experience now as a result of a disease or its treatment define their experienced preferences.

Taking into account patient preferences in the shared decision-making process that relates to the treatment and management of an illness is certainly an attractive concept. After all, as the patients are the end receivers of the ultimate outcomes of the delivered care, they should be able to voice their opinions regarding the care that they receive.¹⁰ Consistently with this view, the terms 'preference-sensitive decisions'¹¹ and 'preference-based care'⁸ have been used to

describe medical decisions in which patients' preferences are critical inputs to the shared decision-making process. Moreover, patients' preferences are increasingly becoming integral to conceptual models of shared decision-making¹² and also to models of 'integrated decision-making'¹³ between doctors and their patients.

This otherwise intuitive reasoning is underpinned by a usually implicit assumption. The assumption is that patients have, or are expected to develop, a firm set of preferences, at first, for their illness and, secondly, for the anticipated outcomes of its treatment. Once this set of preferences is in place, patients can decide if the psychological trade-off between the benefits associated with a successful treatment outweighs the hassles and discomfort arising from it. As Kennedy¹⁴ reported, 'patients are experts in their own field' – meaning that they are experts in the field of their preferences. Others, however, suggested caution, highlighting the consequences of 'large numbers of patients opting for treatments other than those clinically indicated'.¹⁵ Dolan¹⁶ proposed that the anticipation of an illness may be different from the experience of it. In light of this difference, he outlined a dual model for the evaluation of patients' preferences, which assesses the patients' anticipation of an illness separately from their experience of it. The aim of the present review is to contribute to this debate, at first, by summarizing existing behavioural evidence that shows that people's anticipations of future preferences and feelings are often inaccurate and, secondly, by highlighting the relevance of this evidence to shared decision-making. To the best of our knowledge, the relevance of the literature on self-prediction to shared decision-making between patients and their doctors has yet to be demonstrated.

The rest of the review is organized as follows. In Section 2, we summarize behavioural evidence on people's predictions of their future feelings and preferences. The majority of the empirical studies document inaccuracies in these self-predictions. In Section 3, we present the most prominent psychological accounts for the mispredictions. In Section 4, we outline three main empirical questions that a programme

aiming, at first, to enrich our understanding of shared decision-making between patients and their doctors and, secondly, to enhance its practice should address.

Self-forecasts of preferences and emotions

To what extent does an amputation below the knee ruin one's future happiness? Conversely, to what extent does cosmetic surgery on the face improve it? In the social psychological literature, people's current judgements about what their emotions (e.g. happiness, distress, pain, fear) or preferences (e.g. for different health states or treatments) will be in the future are termed 'affective self-forecasting'.¹⁷ A substantial body of empirical research from a range of real life domains (medical and non-medical) demonstrates that people typically exaggerate their emotional reactions to future positive or negative events. The emotions that have been investigated include pain, fear and subjective well-being (or subjective happiness).

Inaccuracies in *pain* forecasts are captured effectively in this excerpt by Schelling:¹⁸

'When we ask the mother who an hour ago was frantic with pain whether she is glad the anaesthesia was denied her, I expect her to answer yes. But I don't see what that proves. If we ask her while she is in pain, we'll get another answer'.

People tend to overpredict a host of different types of pain.¹⁹ Acute pain, such as menstruation pain,²⁰ headache,²⁰ post-operative pain,²¹ dental pain²² and chronic pain, such as arthritis pain²³ and low back pain^{24,25} are some of them.

Overprediction has also been observed in *fear* and *anxiety* forecasts.^{26,27} People overpredict their fear of dental treatments,²² of snakes,^{28–30} of spiders³¹ and of confined spaces.³² In a different context, amateur parachutists have been shown to overpredict their fear before they jump.^{33,34}

Behavioural researchers have also investigated the impact of significant life events and medical results and treatments that affect people's *subjective well-being* and people's forecasts of that impact.³⁵ Both positive and negative events have

been examined. Some empirical evidence suggests that patients who choose to undergo cosmetic surgery are not necessarily happier after it than before.^{36,37} It has also been suggested that patients having to undergo surgically necessary amputations delay or opt out of the operations anticipating that the loss of a limb will permanently ruin their lives.³⁸ In another investigation,³⁹ a group of participants were asked to judge how other people would feel when they had received positive or negative HIV test results. The judging group significantly overpredicted the increase in distress that people with positive results experienced and the decrease in it that people with negative results experienced. In another report,⁴⁰ women were found to overpredict their distress after receiving positive test results for unwanted pregnancies and dieters were found to overpredict their distress after failing to reach their targets in weight loss programmes.

Yet other studies have shown that people overstate the positive impact of a lottery win on their life,⁴¹ the pleasure that they will derive from a future holiday trip⁴² and the happiness (or unhappiness) that they will experience should their favourite sports team win (or lose) a future fixture.⁴³

Psychological accounts for errors in self-forecasts

Why do people consistently fail to predict how painful or fearful a situation will be? Why are we unable to predict how much enjoyment or distress an event will trigger in our lives? Behavioural research has suggested a number of accounts for these phenomena. First, prospective judgements of emotions and preferences fall prey to the *projection bias*. In other words, people underestimate or fail to take into account their ability to adapt to new circumstances. As a result of the underestimation of adaptation, the impact of positive and negative events on the overall levels of well-being is typically exaggerated.^{44,45}

Secondly, when people generate self-forecasts about the impact of a future event on their

subjective well-being, they focus too much on the event in question, thereby neglecting other events that will be co-occurring with the 'focal' one. This *focusing illusion* (i.e. the neglect of future occurrences, which will be competing for attention with the 'focal' event) leads to exaggerated prospective judgements of the impact of future events on people's subjective happiness.^{43,46}

A third account, complementary to the other two, is that there are *evolutionary reasons* that underpin people's affective overpredictions.^{19,26,27,47} According to this explanation, on the one hand, organisms prefer predictable environments to unpredictable ones. The human species seems to have evolved to avoid unpleasant surprises (including surprising fearful and painful stimuli). This explains the pattern of overpredictions for painful, fearful, or distressing events that we anticipate in the future. For these events, we err in the direction of safety – in other words, we strive to avoid unpleasant surprises. On the other hand, organisms seem to have evolved with in-built motivational systems that allow them to pursue a range of rewarding goals. This explains the pattern of overpredictions for pleasant stimuli that we anticipate in the future. For them, we err in the direction of commitment – in other words, we anticipate high rewards in order to commit ourselves to course of action (e.g. the planning that is required for a treatment or for a holiday trip).

The mechanisms that we have discussed in this section are subtly different from each other but can have similar effects. To show this, let us bring them together in the context of the lottery winning example we cited above.⁴¹ Lottery players maintain their motivation for improving their financial situation by overestimating the positive impact of eventually winning the lottery (evolutionary underpinning). By being narrowly focused on the eventual future win, however, the players typically neglect aspects of their lives that the lottery will not affect (*focusing illusion*). Once a player has won the lottery, he or she gets used to being richer (i.e. adapts to it), so the impact of becoming richer gradually diminishes (*projection bias*). It is likely that a combination

of these factors contributes to erroneous forecasts of people's future feelings and preferences. These anticipated feelings and preferences, in turn, shape choices.

Towards more accurate self-forecasts

The behavioural research that we summarized here offers empirical evidence on the pervasiveness of erroneous affective self-predictions. From a clinical point of view, these findings carry implications for shared decision-making between patients and their doctors. Modern systems of health-care delivery aspire to involve the doctor *and* the patient in the decisions that will affect the latter. The doctor approaches the decisions in question armed with clinical knowledge and, ideally, with sensitivity to the psychological aspects of the decision-making process. What about the patients – especially those undergoing painful or distressing procedures (e.g. amputations, chemotherapy)? Whereas a growing number of clinicians and health-care professionals are vocal advocates of shared decision-making, the behavioural evidence suggests that perhaps patients have little insight into their own future feelings and preferences. In other words, patients may *not* be experts in their own field. This is not to say that a more paternalistic view, according to which the doctor should take responsibility for treatment decisions, fares better here. In no way does the evidence that people systematically err in their affective self-forecasts imply that doctors are better equipped than their patients to judge the latter's future 'best interests'. (If anything, behavioural evidence suggests that there are additional difficulties when people attempt to make judgements and decisions for someone other than themselves.⁴⁸)

Where do we go from here? We agree with the suggestion that more research is urgently needed on how patients' preferences shape their choices of treatment.¹⁵ We would add that future research should address at least three interrelated questions. The first one is whether patients are able to predict accurately the impact of an illness and of its treatment on their subjective

well-being. The behavioural research that we reviewed in this study suggests that patients are rather unlikely to be any more accurate than other research participants. The second question that future research should tackle is whether the self-forecasts that patients generate affect their choice of treatments. Existing behavioural evidence suggests that anticipated emotions do affect medical decisions. For instance, people choose not to vaccinate their children against life-threatening diseases if they contemplate the possibility of intense post-decisional regret.⁴⁹ Avoidance of anticipated regret has also been implicated in women's decisions to opt for breast cancer screening⁵⁰ and in cancer patients' decisions regarding their treatments.⁵¹

The final question to be tackled by researchers is whether patients' forecasts could be rendered more accurate. Behavioural research has demonstrated that when people see an event within its context (i.e. embedded in a canvas of other events) they tend to generate more accurate affective forecasts.⁴³ The explanation for this finding is that, by eliciting a context, people realize that the specific event or decision in question is only one among many determinants of their happiness and not necessarily the most important one. In other words, no matter how positive or negative the outcomes of a decision, other, co-occurring life-events will compete with them for attention, thereby reducing their psychological impact (positive or negative). This explanation is consistent with the observation that patients, especially those undergoing or about to undergo long or painful treatment, often seek the advice of other patients who received similar treatment before them. How does such exposure to another patient's experience with an illness and its treatment help a patient reason about his or her own situation? In the light of the evidence we presented above, we think that meeting someone who has had an amputation or who has undergone prolonged chemotherapy is likely to help prospective amputees and cancer patients realize that the operation or the chemotherapy will not necessarily stop them from engaging in a host of every day activities. In other words, being exposed to

other patients' post-treatment experience would allow patients to put a very unpleasant treatment within the context of the rest of their lives. The patients could then realize that what appears to be the focus of their lives at the time of the decision (i.e. the treatment and its consequences) need not be the focus of their lives later on.

This hypothesis is testable. A group of patients who have yet to receive treatment could be asked to describe the affective experience that they anticipate as a result of the treatment (control group). A second, matched group of patients would make the same forecasts, but after having contextualized the outcomes of the treatment ('context' group). This second group could consist of patients who are in contact with a patient or other voluntary organization. Finally, both groups would be asked to report their affective experiences after they have received the treatment. We expect that the control group will mispredict post-treatment emotional experiences, whereas the 'context' group will be more accurate. Importantly, we also expect that the control group will be less likely to opt for the treatment than the 'context' group.

Conclusions

Shared decision-making is a challenging topic, as the Editorial to a recent Special Issue of this Journal devoted to it acknowledges.⁵² It is our hope that the present review contributes to the debate on shared decision-making as a first attempt to highlight the relevance of behavioural evidence on affective self-forecasts to shared decision-making. Although shared decision-making is an intuitively appealing approach to the delivery of care, the robust finding that people often do not judge accurately their future feelings means that successful implementation is not simple. This should not, however, be taken as a rationale against patient involvement or as a reason for paternalism. Clearly, patients deserve to know what an illness and its possible treatment are likely to mean for their future well-being. What the present review emphasizes is the need to accommodate patients' (possibly) exaggerated

self-predictions. Treatments that are invasive (e.g. surgery) or have particularly unpleasant side-effects (e.g. chemotherapy) trigger feelings of dread about one's future emotional state in patients who are about to be subjected to them. In light of such feelings, patients who could benefit from these treatments might opt out, choosing instead not to be treated. How able are different patients to predict accurately the impact of an illness and of its treatment on their subjective well-being? To what extent do such self-forecasts that patients generate affect their choice of treatments? How could such forecasts be rendered more accurate – and how would more accurate forecasts affect choice of treatment? Any programme that aims, at first, to enrich our understanding of shared decision-making between patients and their doctors and, secondly, to enhance its practice should aim to address these questions.

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