

Can I accurately predict the impact of an illness and its treatment on my future subjective well-being? A complex question that does not have a simple answer

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This paper discusses ideas that are worth bringing to the attention of a wider audience to stimulate critical thinking and debate. To summarize the argument, as we understand it, the authors' objective is to highlight the implications for shared treatment decision making of behavioural research which shows that people's predictions of their future preferences, defined as 'positive or negative feelings and emotions' to future events, are not very accurate. In particular, the authors state that people tend to 'overestimate' how negatively or positively they will react to the consequences of a given future event.

Extrapolating from these findings to the process of shared decision making, the authors suggest that newly diagnosed patients facing potential future treatment outcomes with which they have no experiential knowledge may tend to overestimate how negatively they will feel about living with a serious illness and the attendant treatment effects. The authors suggest that, in fact, once patients have experience living with these outcomes, they are likely to realize that they have exaggerated the potential negative impact of these events on their overall level of well-being.

To help rectify this problem of patient 'over-estimation' of the negative effects of adverse health events, the authors recommend that

newly diagnosed patients talk with other patients with the same disease so that the former can help the latter correct their misperceptions. The authors also call for a new research agenda to learn more about patients' abilities to accurately predict their future reactions to such illness events.

The strengths of this paper are twofold. First, it highlights the importance of thinking conceptually about the issue of whether patients can make accurate predictions about living with different treatment outcomes and what this means. Secondly, the paper highlights available behavioural research suggesting that people 'mispredict' their future preferences and the relevance of these findings for better understanding patients' abilities to predict their future subjective reactions to different treatment outcomes. Clearly, both these issues are important to reflect on when considering how patients make treatment decisions. If patients consistently overestimate the negative effects of living with certain treatment outcomes, they might avoid selecting these treatments which might have been more favourably considered, had patients been able to more accurately predict their consequences.

In the spirit of open debate, we would like to raise several conceptual and practical issues concerning the arguments made in this paper. The first issue relates to the inherent difficulties in using aggregate level research data which focuses on population outcomes to predict an individual's behaviour in the medical encounter.¹

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We need to remember that treatment decision making in the medical encounter is not about groups, but rather about a specific individual and there is no direct translation of the meaning of population-based predictions to a given individual patient. Even if we knew from research studies that many patients overestimated, underestimated or exactly estimated what it would be like to live in the future with the consequences of bad outcomes, for example, losing a leg, there is no way of knowing which group this particular patient belongs to and whether she will be able to accurately predict her reactions to future adverse health events.

Just because 70% of the population, for example, have been found to overestimate their future negative reactions to bad treatment outcomes, we have no way of knowing whether this particular patient will do the same. Further, it is unlikely that a time limited conversation between physician and patient in the medical encounter will be sufficient to elicit this information in sufficient detail for the physician to be able to make an accurate prediction of the patient's true future feelings.

If we do not know whether or not this particular patient is able to make accurate predictions, we also do not know whether this is a problem or not for this particular patient, and hence whether and how to intervene to correct it. Moreover, at the time of the encounter, neither the physician nor the patient know the extent to which and ways in which the patient's initial future reactions will change over time, rather than remain stable in the long term.

The question we are left with for the authors is: how can we make population data on patients' abilities to accurately predict their reactions to future adverse health events helpful to any given physician and patient in the medical encounter if we have no way of knowing how these findings apply to a specific patient making a specific treatment decision? In fact, we wonder whether the physician, in this case, may do a disservice to the patient by encouraging her to think in terms of population outcomes, instead of how she might feel in the future, given her

particular lifestyle, experiences and social context.

The second issue we want to raise relates to the recommendation that newly diagnosed patients talk to other more experienced patients with the same disease. Ideally, it would be helpful to newly diagnosed patients to already have some experience with treatment outcomes first and then make the treatment decision based on these experiences. But this is often not possible. As a kind of proxy for this, the authors suggest that newly diagnosed patients talk to others who have had such experiences (how much experience is enough?) and learn what it is like from them as a way of anticipating what it will be like for that individual.

But this view seems simplistic and comes close to assuming that all patients with the same disease develop the same experiential knowledge about living with it, regardless of individual or contextual differences among patients. In reality, patients with a similar disease may have nothing else in common, and in this case, it is unlikely that one such person's experience can be used to accurately predict another's as the differences between them may legitimately explain why they see things differently.

The key issue is finding a 'good match', i.e. talking to a person with enough common ground that her current feelings about living with the disease and treatment outcomes are identical to those that the newly diagnosed patient would have felt if she could have experienced the same outcomes before making the treatment decision (i.e. a 'perfect agent' situation). But like the case of a physician being a perfect agent of her patient, which we know is a theoretical concept that cannot exist in practice,² finding a perfect patient match (or perfect agent) is in practice, impossible. If a 'good match' cannot be found, transfer of experiential knowledge may simply be irrelevant to the latter and/or might cause more harm than good.

We know that variations in patient characteristics can lead to differences in patient predictions about how good or bad the outcomes of different treatments will be. One of the underlying reasons for conducting randomized con-

trolled trials is that these designs control for observable and non-observable variations in the characteristics of patients being studied that can affect outcomes. But, by definition, we do not know what are the unknown characteristics and their impacts on patients' abilities to make accurate predictions. This means that even if we could find a 'good match' on known characteristics, it may still be a bad match in terms of unknown characteristics. This situation raises two key questions for our abilities to make accurate predictions based on others' experiences: how do we find other patients like ourselves and on what variables (i.e. characteristics) is it important to be similar? To the best of our knowledge these issues have not been previously studied and we see these as important areas for future research. We also think it is important that physicians both be aware of the implications of these 'matching' issues and caution patients to think about these rather than steering them to simplistically adopt others' experiences as their own on the basis of a common disease and/or treatment. It is also important to anticipate that in talking to others, the patient considering treatment options may find out that she has underestimated rather than overestimated the negative consequences of the illness.

In summary, this paper describes potential problems with the accuracy of patient predictions of future reactions to adverse health events and this issue is particularly important considering the extent to which current models of shared decision-making rely on patient estimates of their future reactions to different treatment outcomes as a basis for participating with their physician in shared decision making. However, we think that the solutions proposed are somewhat simplistic and may cause more harm than good if the appropriate limitations of these approaches are not considered and made clear to the patient. In this context, it is well to remember H.L. Menken's quote: 'to every complex question there is a simple answer... and it is wrong'.

References

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