The future in clinical genetics: affective forecasting biases in patient and clinician decision making


When clinicians facilitate and patients make decisions about predictive genetic testing, they often base their choices on the predicted emotional consequences of positive and negative test results. Research from psychology and decision making suggests that such predictions may often be biased. Work on affective forecasting – predicting one’s future emotional states – shows that people tend to overestimate the impact of (especially negative) emotional events on their well-being; a phenomenon termed the impact bias. In this article, we review the causes and consequences of the impact bias in medical decision making, with a focus on applying such findings to predictive testing in clinical genetics. We also recommend strategies for reducing the impact bias and consider the ethical and practical implications of doing so.

Conflict of interest
The authors declare no conflicts of interest.

A 33-year-old man whose father died of a neurodegenerative disease contemplates having genetic testing that may consign him to or clear him of the same fate.

A couple wanting to have a family decides whether to have carrier testing which will determine if a hereditary illness will be passed on to their children.

A young woman whose mother has a hereditary breast cancer mutation decides whether to have testing herself, which would determine whether she would have an increased risk of developing cancer.

Scenarios like these are common in the practice of clinical genetics. All involve predictive testing, whereby a healthy patient is tested for a possible predisposition to a disease. Clinical geneticists and counsellors coordinate interviews with test candidates to explain alternatives and advise patients on suitable courses of action, potentially based upon the outcomes of such testing. How best to do this while minimising harm is still a focus of much clinical genetics research.

Decision theory suggests that choices such as those described above will be driven in large part by how people evaluate the costs and benefits of different options: people will prefer options that they predict will have positive outcomes and avoid options that they predict will have negative outcomes (1). Other barriers to testing may feature in these decisions, such as availability (2), risk perceptions (3, 4), competing life concerns (5) and insurance issues (6, 7). However, some research suggests that people often simplify complex genetic risk estimates by using simple heuristics (8, 9). In this article, we argue that the preferences that
feature in decisions such as those above are subject to prediction biases. In making decisions, people have to predict or forecast how certain events or outcomes will impact their own or others’ well-being. Research from psychology and decision making suggests that such forecasts are subject to systematic biases that may promote an overly risk-averse stance on predictive genetic testing, both on the part of patients and clinicians. In presenting our case, we (i) review research on affective forecasting biases in medical decision making, (ii) consider specific applications of this research to clinical genetics and (iii) review potential intervention strategies aimed at reducing forecasting biases in clinical genetics.

**Forecasting biases in medical decision making**

The process of predicting how one will feel in the future – affective forecasting – is subject to bias; people are not always accurate in predicting the emotional impact of future events (see Ref. (10–12) for reviews). They get the emotional valence (positive or negative) right, and are good at predicting the immediate intensity of their future emotional reactions (13), but they systematically overestimate the durability and intensity of the affective impact of events on their well-being. This tendency has been called the impact bias and has been shown for forecasts in a variety of domains including politics (14), consumer choice (15), personal relationships (16) and intergroup relations (17). Although in evidence for both positive and negative emotional forecasts, the impact bias tends to be larger for aversive events (18).

There is growing evidence of the impact bias in the medical domain (see Ref. (19, 20) for reviews). For example, people overestimate the positive impact of kidney transplants (21); the emotional impact of positive human immunodeficiency virus (HIV) test results (22); and the negative emotional impact of haemodialysis (23, 24). Similar results have been found for a range of other conditions: paraplegia (25), colostomy (26), diabetes, haemophilia, kidney disease (27) and acne (28). The general tendency for healthy people to overestimate the negative emotional impact of health conditions (compared to patients’ own ratings) has been termed the disability paradox (29) and has been considered an example of impact bias. Furthermore, people overestimate the intensity of dental (30), arthritic (31) and menstrual pain (32); yet other work has considered the role of forecasting biases in advance care planning (33, 34).

There are two dominant proposed contributory causes of the impact bias. The first, focalism (also known as the focusing or focal illusion, (35)), is the tendency to focus on the affective consequences of a single, focal future event, while ignoring the emotional impact of non-focal events on well-being (36). Research (27) shows, for example, that the predicted emotional reactions of healthy people to a future diagnosis are more extreme than the actual reactions of matched controls who already have a chronic illness. This is due to participants focussing exclusively on the negative consequences of the disease itself (the focal event), while underestimating the mitigating influences of other aspects of life, such as family and work, on well-being.

The second contributory cause of the impact bias is immune neglect (37). This is the failure to anticipate how easily and quickly we make sense of and adapt to negative events; in other words, people are resilient but are unaware of it (38). Research suggests that just as we have a physiological immune system which fights threats to our internal environment, we also have a ‘psychological immune system’ which fights threats to our emotional well being. This includes a range of coping resources such as mastery, social support and self-esteem (39) and coping strategies such as rationalisation, motivated reasoning, self affirmation and positive illusions (37, 40–42). These defensive mechanisms are largely unconscious, and so we do not take sufficient account of them when predicting our future emotions.

It is important to note that the impact bias may lead patients, as well as clinicians and policy makers, to overestimate the negative consequences of various medical interventions, resulting in a culture of risk-aversion in which patients may be opting out of potentially beneficial diagnostic and treatment regimes. In a group of patients receiving HIV tests, anticipated emotional responses to a positive test result were more extreme than those actually experienced, and this overestimation prevented some from undergoing the test (22). Other work (43) suggests that patients may overestimate the pain and/or embarrassment associated with a colonoscopy, which may serve as a barrier to screening.

**Forecasting biases in predictive genetic testing**

Despite a growing body of research on forecasting biases and their consequences in the medical domain, no work has systematically considered such biases in clinical genetics. (See Ref. (44, 45) for a brief discussion of prediction biases in the genetic testing of children). Nevertheless, there are strands of research that are suggestive of the operation of the impact bias in clinical genetics.

Current practice in clinical genetics is geared towards minimising the negative psychological outcomes of testing practices by a process of education and demystification, as well as via pre- and post-test counselling. Interestingly, results of extensive research into the affective reactions of patients undergoing predictive genetic testing suggest that psychological outcomes are not as negative as one may expect (46–48). Studies show that patients who are found to be carriers for a genetic disease differ from controls in psychological measures of distress in the early time period after receiving a result, and that these measures return to baseline over time. (e.g. Huntington’s: 49–51; BRCA: 52–54; HNPCC: 55). Most studies show that people cope well with positive test results (In this article, ‘positive test result’ refers to the presence of a genetic mutation or defect and constitutes a ‘negative outcome.’ A ‘negative test result’ refers to the absence of a genetic
defect and is a ‘positive outcome.’) often deviating little in psychological parameters from baseline controls (56). In short, people may be better at coping with negative events than they realize.

Specific concerns for clinical genetics

In addition to the general issues raised above, we argue that there are a number of particular properties of predictive genetic tests that amplify concern about the role of forecasting biases.

First, most predictive testing is done on pre-symptomatic and often currently healthy people. As work on the ‘disability paradox’ suggests, healthy people typically overestimate the negative impact of health states compared to patients suffering from such states (29). Furthermore, healthier people anticipate worse quality of life (QoL) as a consequence of future poor health than do sicker people (34). To the extent that predictive tests are done on currently healthy people (rather than on patients who may already have some manifestations of a condition), impact biases may be exacerbated.

Second, given the significant role that clinicians (especially doctors) play in advising their patients, the question of empathic forecasting (i.e. forecasting for someone other than the self) is pertinent. The research discussed thus far has focused on forecasting biases for the self. What happens when we forecast for others? How do clinicians explore the potential impact of a positive (or negative) test result on their patients’ lives?

A recent study recognised that our current methods are often inaccurate in predicting who will be most vulnerable following a test result and thus who will request psychological help (57).

The evidence on empathic forecasting is mixed. Some research shows that we are worse at forecasting for others than for ourselves (58); which suggests that the impact bias may be greater when making predictions for others (e.g. clinicians for patients). However, other work suggests that people predict that health conditions such as diabetes, epilepsy and haemophilia will more adversely impact their own lives than the lives of others (27); and yet other work (59) suggests that impact biases for self and other predictions are of similar magnitude. On the whole this research suggests that the impact bias is, at the very least, operative when making forecasts about the impact of aversive events on others’ lives; clinicians may be subject to such empathic forecasting biases when considering how others will respond to the outcomes of predictive tests.

Third, given the hereditary nature of genetic diseases, patients undergoing predictive testing are likely to have family members with the disease and therefore direct experience with the condition in question. On the one hand, a particularly negative experience of a family member with the disease may serve to amplify the impact bias, although on the other hand witnessing a family member cope well with the condition may lessen the bias. (See below for further discussion.)

Consequences in clinical genetics

Given that the factors reviewed above suggest that the impact bias may influence decision making in a clinical genetics setting, and that research shows that the impact bias may prompt a risk-averse approach to certain medical procedures, it follows that some patients may be less inclined to attend genetic counselling and/or opt for testing. Indeed there is some evidence that genetic testing in the general population and in families with known hereditary diseases is under-utilized (60–62); the impact bias may play a role in such under-utilization.

Research shows that the majority of patients expect the worst when it comes to testing. Most at-risk women undergoing genetic testing for breast cancer believe they will test positive (63); distress and anxiety levels in patients receiving counselling for BRCA genes are elevated in those who are not tested but who are nonetheless aware of their potential risk (64, this replicates in studies of Huntington’s disease, 48). Furthermore, in the face of uncertainty (i.e. before testing), the psychological costs of holding negative expectations are substantial (65).

In addition to the costs of uncertainty, there are benefits of certainty. Numerous studies relating to the BRCA genes, as well as Huntington Disease, have shown that those receiving negative test results (i.e. no mutation) show a significant improvement in psychological well being across all parameters (49, 55, 64, 66–71). There are also benefits to receiving a clear positive test result, such as the initiation of coping mechanisms, reproductive options (e.g. pre-implantation genetic diagnosis) and interventions (e.g. enhanced screening and risk reduction surgery). It should be noted, of course, that a positive test result, while providing certainty on genetic status will not always lead to certainty on disease risk and progression (72). To the extent that the impact bias leads patients to opt out of testing and remain in a state of psychological uncertainty, it may be responsible for significant psychological distress among patients.

Reducing the impact bias

Despite the prevalence of forecasting inaccuracies, research does show that the size of the impact bias is moderated by a number of individual difference, cross-cultural and situational factors (73–77). Knowledge of such moderating factors may give insight into interventions that may successfully reduce bias. Of particular, relevance to potential interventions are findings that aspects of emotional intelligence (especially emotion management; 78) and mindfulness (especially observing one’s internal states, 79) increase forecasting accuracy.

Of more, immediate practical import are interventions aimed directly at reducing focalism and immune neglect. Notwithstanding the techniques employed by genetic counsellors grounded in a wide range of counselling theory, exploring focalism and immune neglect
Defocusing literature seems warranted. Defocusing (e.g. by keeping a ‘prospective diary’ of non-focal future events) has been shown to have some efficacy in reducing the impact bias in laboratory contexts (36); however, evidence for the utility of defocusing in medical decision making is mixed. Some research (80) has found that asking people about how having paraplegia would impact their experiences of a range of everyday activities (such as travel, visiting friends and family, paying bills) increased the impact bias. In an attempt to reconcile these findings with other work suggesting the efficacy of defocusing, another study (81) found that exposing people to a concrete, day-in-the-life narrative about someone who had experienced the to-be-forecasted event, decreased the extensity of forecasts. When people are asked about abstract activities like travel (as in Ref. (80, 82)), they may be inclined to think of how the focal event might negatively impact those other life domains, rather than how those other life domains might be unaffected or indeed mitigate the negative impact of the focal event.

Another approach to reduce the impact bias is making people aware of the operation of the psychological immune system. Interventions that raise awareness of the diversity of coping strategies that people use (especially those used in the immediate aftermath of a negative event, Ref. (42)) may help reduce immune neglect, and, in so doing, decrease the impact bias. For example, participants who were asked to recall how their emotions had changed in response to past experiences were less subject to the impact bias (80). Furthermore, having participants talk to others who have experienced an event increases the accuracy of forecasts, in part because such discussion highlights the power of the psychological immune system (37).

Support groups in which patients can talk to others with positive test results may highlight the coping strategies at one’s disposal. There may, however, be limits to the effectiveness of providing surrogate information (such as first-person narratives), as people may discount such information in the face of more pertinent, event-related information based upon personal or vicarious experience with the disease (27).

There is also some evidence that simply alerting people to the role of the psychological immune system and of the tendency towards focalism may help reduce the impact bias. In one study (43), participants were presented either with a first-person narrative describing the experiences of a similar other with a particular medical procedure (colonoscopy) or with a non-narrative, factual message about the same procedure. Importantly, the narrative also contained statements about the role of the psychological immune system (e.g. ‘whatever happens – I’ll deal with it just like I deal with everything else’) and prompting defocusing (e.g. during the screening experience ‘I got to catch up on my reading’). Compared to non-narrative controls, participants in the narrative condition perceived less potential impact of screening barriers on their behaviour and, importantly, expressed greater interest in screening in the future. Although the study design does not allow us to pinpoint the operative factors in these effects (narrative structure, narrative content, immune system awareness, defocusing or some combination of these), it points to a reasonably straightforward strategy that may decrease the impact bias.

Although the techniques outlined above may go some way to reducing the impact bias, two important questions remains: (i) should we attempt to reduce the impact bias in clinical genetics decision making? and (ii) how are such lab-based procedures best put into practice? These questions are largely beyond the scope of this review; we do, however, we offer a few remarks.

The ethical acceptability of reducing the impact bias in medical decision making has received some treatment (83–85). Common ground in this discussion is the acceptance of the need to respect patients’ decisions when they have decisional capacity. The question at the heart of the debate, however, is whether the impact bias reduces decisional capacity. While some suggest that forecasting biases are capacity impairments and that some degree of paternalism may be warranted to reduce such biases (84, 85), others argue that forecasting biases pose no threat to decisional capacity (83).

If we are to attempt debiasing, how best to put theory into practice? The work on narrative discussed above (43) is promising in that it shows that embedding information that defuses immune neglect and focalism within a narrative may help debias judgements somewhat. Such narrative-based interventions would be simple enough to incorporate into counselling sessions and patient decision support interventions. Work on practical interventions for forecasting biases is in its infancy and application of knowledge gleaned from research is best addressed via ongoing dialogue between practitioners and researchers (86).

Although questions of ethical acceptability and practice remain moot, we think it is of use for clinicians to know that forecasting biases exist, both in their own and in their patients’ decision making. Exactly how that knowledge should be put into practice, if at all, remains an important, open question. Genetic counselling is an important aid for patients and their families in making decisions regarding gene testing. However, the potential to cause harm may be over-estimated and it is important that in the counselling process we are aware of the potential operation of focalism and immune neglect. To the extent that the impact bias prompts patients to opt out of testing, they may suffer more sustained psychological distress in terms of uncertainty and an inability to take positive action. Of the numerous biases at play in medical decision making, the impact bias is of particular significance for clinical genetics. It is important that clinicians are aware of its potential influence when evaluating policy and counselling their patients.

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