



BMJ Open Are patients accurate forecasters of their emotional response to medical conditions? A scoping review on affective forecasting

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ABSTRACT

Objective In this paper, we challenge the premise that patients are capable of accurately predicting their emotional response or quality of life in anticipation of health changes. Our goal was to systematically review the published empirical evidence related to the reliability of affective forecasting in the context of medical conditions.

Design Scoping review.

Setting We conducted a search string using both simple search terms as well as MeSH terms and searched the electronic databases of PubMed, Embase, CINAHL and Cochrane up to April 2021.

Participants We initially selected 5726 articles. Empirical studies reporting on predicted and/or observed emotions or quality of life concerning deterioration, improvement in health or chronic illnesses were included. Furthermore, empirical studies of healthy individuals predicting emotional response or quality of life compared with patients reflecting on emotions or quality of life concerning deterioration or improvement in health or chronic illnesses were also included. Studies on healthy participants, psychiatric patients and non-English articles were excluded.

Results 7 articles were included in this review. We found that patients generally tend to systematically exaggerate both anticipated happiness and sorrow/grief after health improvement and deterioration, respectively.

Conclusion Patients are less adept in predicting emotional response or quality of life regarding to health changes than we are inclined to assume. We discuss several biases which could explain this phenomenon. Our findings are relevant in the context of treatment decisions, advanced care planning and advanced care directives.

INTRODUCTION

The discussion of future health conditions plays a central role in prevailing paradigms of informed and shared decision making. Fundamentally, these paradigms seemingly rely on the premise that patients possess the ability to reliably predict their future emotional response and well-being in an anticipated health condition. For example, people engage in advanced care planning

Strengths and limitations of this study

- This is the first scoping review to systematically explore if patients are capable of accurately predicting their emotional response and/or quality of life after health changes.
- A multidisciplinary team of ethicists, a librarian, psychiatrist, physicians in different areas of the field worked on this review.
- A comprehensive search strategy has been developed in consultation with a health librarian to overcome the lack of terminology consensus and appropriate MeSH terms in the medical field.
- While there may be little published empirical work in this field, all included studies point to directionally similar conclusions which may match the daily experience of physicians in the field.

(ACP) and may issue advanced directives in anticipation of situations in which they may be less able to express themselves, such as during critical illness. More commonly, however, situations occur, where the anticipated emotional response to specific outcomes determines choice of treatment. In psychological science, predicting your future emotional response to an anticipated situation or condition is referred to as affective forecasting (AF).^{1–5} One's future emotional response to health decline and disability is arguably an important determinant of quality of life. These can be measured using validated questionnaires as EuroQoL-5 Dimension or the use of various scales such as the Self-Anchoring Striving Scale or the Quality of Life Scale.^{6–8}

How should physicians respond to patients expressing predicted emotions related to changes in health? What if, for example, a patient foregoes mastectomy, insisting that it will make her unhappy. Intuitively, it does not seem appropriate to doubt or even challenge

a patient's affective response and personal beliefs. However, the question if patients predictions are reliable seems relevant from the perspective of good counselling.

There is increasing evidence in the field of psychology that individuals are not the best predictors of their appreciation of quality of life in hypothetical situations. Multiple cognitive biases concerning AF have been described, including projection bias (to project current preferences onto future events or situations), focalism (focusing on what gets worse, not what remains positive) and immune neglect (underestimation of one's adaptive capacity).¹⁻⁵ Small studies outside the medical context support these cognitive biases.⁸⁻¹⁴ Together, biases in AF may explain counterintuitive phenomena such as the 'disability paradox': excellent quality of life despite serious and persistent disability. The importance of AF in medical decision making and knowledge of the aforementioned biases raise the question of what is empirically known about the reliability of AF. Therefore, our aim was to systematically review the published empirical evidence related to the reliability of AF in the context of medical condition. In the context of this paper, AF is defined as the action or process of conducting predictions for future emotional response and/or quality of life.

METHODS

Studies were selected according to the criteria outlined below.

Search strategy

The electronic databases of PubMed, Embase.com/CINAHL and Wiley/Cochrane Library were searched from inception up to April 12th 2021, using a search strategy involving both simple search terms as well as hierarchical family forms (eg, MeSH). The strategy was developed together with a medical information specialist, combining terms closely related to 'AF' in title and abstract. The comprehensive general search encompassed the core semantics of AF in the clinic. The following three core elements were distilled from the term AF: (1) (clinical) decision making, (2) emotions or feelings and (3) forecasting or predicting. The search strategy combinations of key terms are stated per database in online supplemental appendices 1.1 to 1.4.

Patient and public involvement

This is a scoping review on existing literature. No individual-level data were involved in this study or in defining the research question or outcome measures.

Selection criteria

Empirical studies reporting on predicted as well as observed emotions or quality of life concerning deterioration or improvement in health or chronic illnesses were included. Furthermore, empirical studies of healthy individuals predicting affect or quality of life compared with patients reflecting on emotions or quality of life

concerning deterioration or improvement in health or chronic illnesses were included as well. Studies reporting exclusively on healthy participants, psychiatric patients suffering from disorders which have been shown to influence AF such as schizophrenia and major depression, studies on the effect of interventions on biases in AF, retrospective studies on experiences with medical decisions such as watchful waiting and non-English articles, were excluded.

Data extraction

All articles were screened double-blind by two reviewers independently by using online based software that facilitates blind collaboration among reviewers.¹⁵ Titles and abstracts were screened. When titles or abstract were not sufficiently informative, the full article was read to determine eligibility for inclusion. When in doubt the decision was made after discussion between two authors. The reference lists of the included articles were cross-checked to find additional articles and the 'cited by' list on PubMed was checked for additional relevant articles. Two reviewers independently evaluated the methodological quality of all included studies (online supplemental appendix 2). Methods and reporting were fully aligned with existing criteria for scoping reviews (online supplemental appendix 3).¹⁶

RESULTS

The results of the search strategy are shown in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow chart (figure 1). Study characteristics of included studies are shown in tables 1 and 2. The articles are divided in two groups. Group 1 containing articles with a longitudinal (within-subject) design and group 2 containing articles with a cross-sectional (between-subject) design. In both groups, the focus of studies was not on specific aspects of emotional response to health changes, but rather on the predicted quality of life in the future health condition.

Group 1: within-subject design

No studies were found on the accuracy of predicted quality of life, in conditions associated with gradual progressive deterioration, such as neurodegenerative diseases. However, there is some research on the predicted effect of specific medical interventions on quality of life.

Although the sample size is limited in all included studies, the overall pattern suggests overestimation of quality-of-life effects. This is shown for example in the kidney transplant study, in which the predicted improvement in quality-of-life by transplantation was significantly larger than the actual improvement.¹⁷ The study on effect of spinal surgery on chronic back pain echoes this pattern,¹⁸ as does the study on the difference in having mastectomy with or without reconstructive surgery.¹⁹

Group 2: between-subject design

The included studies in group 2 show a tendency of healthy individuals to underestimate the quality of life of

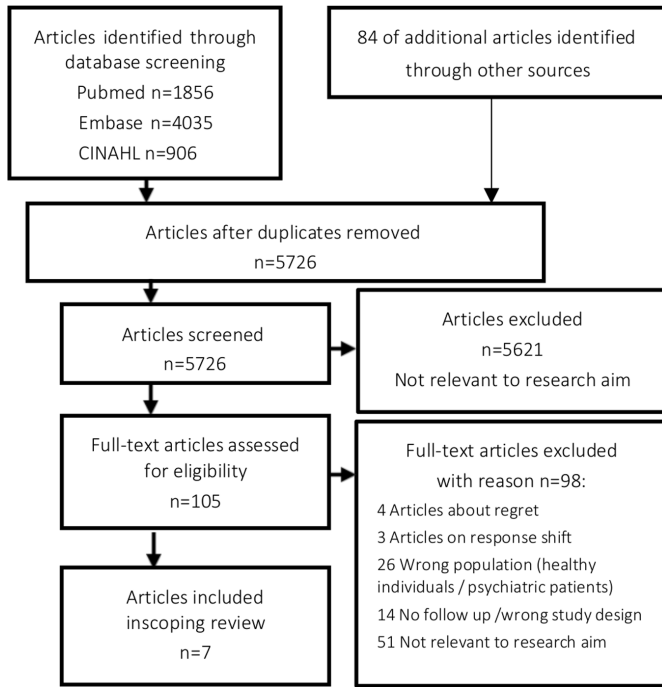


Figure 1 PRISMA diagram depicting the flow of information through the different phases of the systematic review.¹⁶ PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

patients. This type of bias is observed in healthy individuals compared with patients, but also in studies comparing patients to patients, echoing the pattern in group 1. The colostomy study suggests that even former patients tend to underestimate their quality of life during the time they were patients.²⁰

DISCUSSION

This study reviewed, for the first time, the empirical evidence addressing reliability of AF regarding medical conditions. The first conclusion is that very little empirical research has been done on this topic, especially in a longitudinal (within-subject) design. No studies seem to have been done in the field of progressive (neuro)degenerative diseases, whereas this disease category is intuitively very relevant for this topic. The empirical research that is available largely focuses on anticipated quality of life, of which the predicted emotional response to the projected health condition is, intuitively, the main determinant. Second, this review reveals a pattern, in both healthy subjects and patients, of overestimation of predicted quality of life in cases of anticipated improvement, as well as underestimation of quality of life after anticipated health deterioration.

The pattern of ‘exaggeration’ of the impact on quality-of-life by health changes is supported by the literature outside the medical field. For example, people overestimate the hedonic feeling of a prize they do not expect to win.⁹ Track athletes overestimate the intensity of negative emotions when losing a race, but are capable of quite

| Table 1 | | Within-subject design | | Sample size | Time of assessments | Methods of measurement | Conclusion |
|---|---------|--|----|--|--|---|------------|
| Smith <i>et al.</i> , 2009 (Part 1) ¹⁷ | USA | Prospective, longitudinal study on QoL in patients before and after kidney transplant | 33 | Baseline, 6 and 12 months | <ul style="list-style-type: none"> ▲ Interviews ▲ QoL rating scale ▲ Measurement of physical and mental health functioning | <p>An improvement of QoL after transplantation was predicted and indeed occurred yet mean predicted QoL after 12 months was 8.5 points higher (scale: 0–100) than actual QoL.</p> | |
| Damsgaard <i>et al.</i> , 2016 ¹⁸ | Denmark | Within-subject design studying the effect of spinal surgery on QoL in case of chronic backpain | 10 | 1. 2–3 days after surgery 2. 2 months after surgery | <ul style="list-style-type: none"> ▲ Semistructured interviews and observations | <p>Despite most patients being largely pain-free after surgery; sadness returned in several patients.</p> | |
| Lee <i>et al.</i> , 2018 ¹⁹ | USA | Prospective cohort survey study on the accuracy of predicted well-being of patients undergoing mastectomy with, or without immediate breast reconstruction | 96 | Baseline and 6, 12 and 18 months after surgery | <ul style="list-style-type: none"> ▲ Surveys based on: Cantril Ladder for happiness ▲ Breast-Q ▲ Satisfaction with Decisions and Decision Regret Scale ▲ For QoL numeric rating scale of 0–100 | <p>Women scheduled for mastectomy without reconstruction (n=54) predicted an 8.6 point decrease in overall QoL after surgery. Their actual QoL after surgery was on average 6 points (scale 0–100) higher than predicted. In women scheduled for mastectomy with reconstruction (n=42), actual QoL was significantly lower than predicted in the domains ‘satisfaction with breasts’ (0.5 point (scale 1–4)), ‘sexual attractiveness clothed’ (0.4 point (scale: 1–5)) and ‘sexual attractiveness unclothed’ (1 point (scale: 1–5))</p> | |

QoL, quality of life.

Table 2 Between-subject design

| Source, year | Country | Population studied | Sample size | Methods of measurement | Conclusion |
|--|-----------------|---|---|---|--|
| Ritis <i>et al</i> , 2005 ³³ | USA | Patients with end-stage renal failure (average of 3.3 years on dialysis) receiving haemodialysis treatment compared with healthy individuals imagining life under haemodialysis | 49 patients, 49 healthy controls | <ul style="list-style-type: none"> ▲ Questionnaire of mood levels, using levels and scales (-2 to +2 scale) ▲ Ecological momentary assessment through personal digital assistants | Healthy individuals predicted a mood decrease of -1. In anticipation of dialysis compared with the measured mood of dialysis patients. Dialysis patients imagined a 0.46 higher mood score when imagining being healthy, which was 0.33 higher compared with the actual mood score of healthy controls. |
| Smith <i>et al</i> , 2006 ²⁰ | USA | Current patients with colostomy /ileostomy compared with former patients and to healthy individuals | 195 patients of whom 100 had their colostomy reversed 567 community samples recruited from an Internet panel | <ul style="list-style-type: none"> ▲ Survey including-Quality of Life scale ▲ Life Satisfaction scale ▲ Positive Affect/Negative Affect Scale (PANAS) ▲ Ladder scale /self-anchoring striving scale ▲ Time trade-off utility measure, (scale 0–119 months) | Former patients were willing to trade an average of 43 months of their lives in exchange for living without a colostomy, compared with 19 months for current patients. The community sample was willing to trade an average of 44 months. No significant difference was observed in quality of life between current and former patients. |
| Smith <i>et al</i> , 2009 (Part 2) ¹⁷ | USA | Patients waiting for kidney transplant compared with patients after kidney transplant | 307 | <ul style="list-style-type: none"> ▲ Quality of life scale (scale: 0–100) ▲ Physical and mental health functioning (Short Form Health Survey-12) | Improvement in quality of life in post-transplant patients was 12.3 points lower than predicted by pre-transplant patients. |
| Peeters <i>et al</i> , 2011 ³⁴ | The Netherlands | Patients with rheumatoid arthritis (RA) compared with healthy individuals imagining having RA based on a health state description | 124 patients and 65 healthy individuals recruited by advertisement in newspaper | <ul style="list-style-type: none"> ▲ Interviews and questionnaires leading to self-named domains ▲ EuroQol-5D questionnaire ▲ Illness Cognition Questionnaire | Healthy individuals ranked the EuroQol-5D dimensions 0.75% median lower compared with patients. |
| Goranson <i>et al</i> , 2017 ³⁵ | USA | Blogs of terminally ill patients compared with forecasts of everyday people imagining themselves in a similar condition | Cancer: n=20 Amyotrophic lateral sclerosis: n=5 Healthy: n=45 | <ul style="list-style-type: none"> ▲ Linguistic Inquiry and Word Count programme ▲ PANAS and rating scale (1-5) | Healthy forecasters used 1.7% more negative-affect words than terminal patients. This difference was not found in the use of positive-affect words. |

EuroQoL-5D, EuroQoL-5 Dimension.

accurately predicting positive emotions when winning a race, causing some researchers in the field of psychology to argue that people may be capable of accurate AF in specific circumstances.^{14 21 22} As supported by our findings, cognitive bias does not only affect anticipated emotions and quality of life, but may also influence patient's assessment of their past well-being. In several studies, for example in neurological or kidney disease, patients tend to underestimate their earlier quality of life.^{23 24}

Articles on psychiatric conditions were excluded in this review since these conditions may themselves directly affect people's forecasts and emotions such as in bipolar disorder and major depression, even when in remission.²⁵ Nonetheless, research on AF in this field provides interesting context to our findings. Psychiatric patients overestimated the intensity of both positive as well as negative forecasts just as in other studied groups, both clinical and non-clinical.²⁶ In patients with dysphoric symptoms, the exaggerated prediction of negative affect during these states was stronger correlated than in other subjects, leading the authors to suggest what they call the dysphoric forecast bias.²⁷

Possible explanations for the overestimation of improvement and deterioration

The pattern in group 1 and partly group 2 of our study shows that people underestimate their anticipated quality of life in imagined deteriorated health states, and that former patients are subject to a similar type of bias. A combination of multiple mechanisms, together referred to as impact bias, is likely responsible for this. Impact bias causes people to misjudge the impact of change in their lives in both intensity and durability. Underlying mechanisms may include immune neglect, focalism and response shift. In immune neglect, patients underestimate the extent to which their coping mechanisms mitigate emotional suffering. By focusing on what changes, people tend to neglect that in time other unrelated events will occur, which may positively influence happiness: focalism.²⁸ Response shift refers to the phenomenon that people fail to acknowledge that, after substantial life changes, new values are formed, replacing the values that are lost. In other words, response shift is a kind of re-prioritisation of one's values. The phenomenon is found in, for example, patients with cancer and Japanese elderly who consider end-of-life care under deteriorating physical conditions.^{29 30}

There is no literature known to us that directly explains the phenomenon of exaggeration of anticipated improvement. Yet it seems plausible that similar mechanisms that play a role in anticipated deterioration, particularly focalism and response shift, also do so in anticipated improvement.

Limitations

The literature search was complicated by a lack of terminology consensus and, hence, appropriate Medical Subject Headings (MeSH) terms. AF is a well-known term

in the field of psychology, but not in the medical field. We tried to overcome this problem by rebuilding a broad MeSH term library using terms of included articles.

Despite our broad search string and over 5000 results, only 7 articles were included. However, all studies identified pointed to directionally similar conclusions: overestimation of predicted quality of life in cases of anticipated improvement and underestimation of quality of life after anticipated health deterioration. Furthermore, our findings are consistent with the studies in the field of psychology. The lack of studies in the medical field indicate the need for further research in this area. It may also be useful to question patients not just on their anticipated overall quality of life, but also on their predictions as to how they expect to respond emotionally specifically to the altered health condition in question.

Clinical implications

In for example end-of-life discussions, such as ACP, practitioners count on patients having more or less stable preferences. This stability, however, becomes critical when the patient indeed becomes incapacitated. Stable preferences can represent past choices which no longer reflect core values—or may actually never have—when confronted with a real-world situation.³¹ Research on patients stated values in case of life sustaining treatments confirms this, showing a discordance between peoples stated values and their preferences, leading to decisional conflict. This raises questions about patient's ability to recognise or anticipate conflicts between their own values.³²

Although clearly more empirical research is needed, the reliability of patient's AF in the health context seems questionable. This raises several issues for clinical practice. First, healthcare workers are advised to at least mitigate patients expectations of both anticipated health improvement as well as health deterioration. In other words, stimulate your patients not to overestimate their happiness after (partial) cure, nor their suffering after health declines. Second, although speaking about possible future health scenarios and what medicine could do if they arise is obviously sensible, we may question if engaging in advanced care directives (deciding on future care) should be encouraged in all patients. In particular, insofar as decisions may not be reversible when the anticipated condition is imminent, physicians may recommend caution when patients engage in anticipatory decision making. Examples included anticipatory decisions on life sustaining treatment (eg, mechanical ventilation, cardiopulmonary resuscitation) based on perceived quality of life if such treatments are successful, but some degree of incapacity persists. Expectations regarding the effect on a patient's well-being should be thoroughly discussed, taking the risk of biased thinking explicitly into the equation. Making this subconscious bias part of the discussion may persuade healthcare workers and patients to make decisions at the time they must be made, rather than long before. The ethical friction obviously occurs when patients beliefs are strong, and challenging those beliefs

may cause resistance on the part of patients or their families. Healthcare workers should find middle way between challenging these beliefs and respecting patients autonomy. The doctor's experience with other patients predicting the same emotions but experiencing much more positive ones may provide an opening to further discussion.

Conclusion

There is surprisingly little empirical evidence on the subject of AF in medicine. This review casts doubt on the reliability of AF and suggests bias in terms of exaggeration of both anticipated happiness and sorrow after health improvement and deterioration, respectively. It seems patients are less apt in making predictions regarding emotional responses to health changes than we are inclined to assume. This challenges the dogma of ACP and advanced care directives. Future research should focus on longitudinal studies comparing anticipated vs experience quality of life in progressive disease, such as amyotrophic lateral sclerosis. This will contribute to better counselling for both doctor and patient.

Contributors GJvdB and RANR have made substantial contributions to conception and design and analysis and interpretation of data. They have been involved in drafting and revising the content, gave final approval for the version to be published and agreed to be accountable for all aspect of the work. GJvdB and RANR have contributed equally to this work and are both guarantor. RO has been involved in rebuilding a broad library to overcome the lack of terminology in the medical field. He revised the content and gave final approval for the version to be published and agreed to be accountable for all aspect of the work. CB has been involved in the interpretation of data, revised the manuscript critically for important psychological intellectual content, gave final approval for the version to be published and agreed to be accountable for all aspect of the work. YMS has been involved in the whole process from start to end by contributing to the conception, analysis, and interpretation. He revised the work and manuscript critically for important intellectual content, gave final approval for the version to be published and agreed to be accountable for all aspect of the work.

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