BMJ Open

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

G J van den Bosch ,[1] R A N Roos,[2] R Otten,[3] Claudi Bockting ,[4] Y M Smulders[5]

To cite: Bosch GJv, Roos RAN, Otten R, *et al*. Are patients accurate forecasters of their emotional response to medical conditions? A scoping review on affective forecasting. *BMJ Open* 2021;**11**:e053370. doi:10.1136/bmjopen-2021-053370

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (http://dx.doi.org/10.1136/bmjopen-2021-053370).

GJvdB and RANR contributed equally.

GJvdB and RANR are joint first authors.

Received 17 May 2021
Accepted 12 November 2021

[1]Noordwest Ziekenhuisgroep, Alkmaar, The Netherlands
[2]UWV, Amsterdam, The Netherlands
[3]Amsterdam UMC Locatie VUmc, Amsterdam, The Netherlands
[4]Department of Psychiatry, University of Amsterdam, Amsterdam, The Netherlands
[5]Internal Medicine, Amsterdam UMC Locatie VUmc, Amsterdam, The Netherlands

Correspondence to
G J van den Bosch;
gj.vanden.bosch@nwz.nl

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.

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.

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 (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

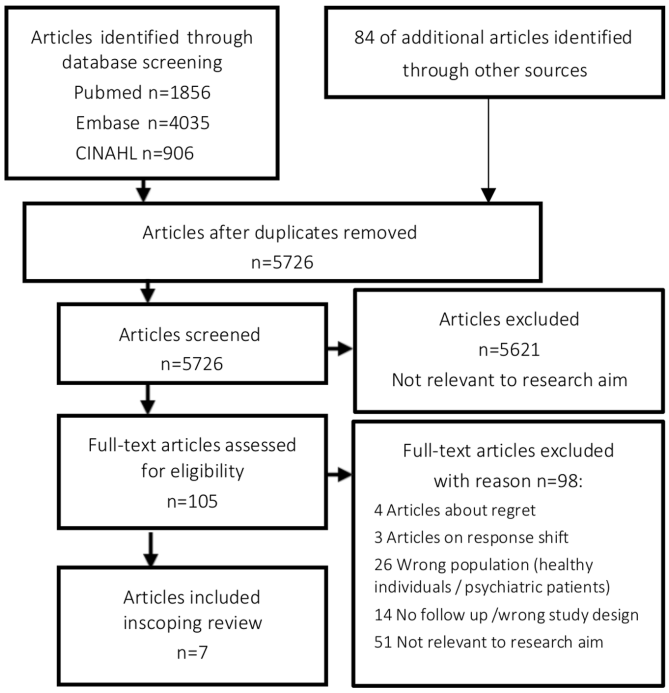

Figure 1 PRISMA diagram depicting the flow of information through the different phases of the systematic review.[16] PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

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 price 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

Source, year	Country	Population studied	Sample size	Time of assessments	Methods of measurement	Conclusion
Smith *et al*, 2009 (Part 1)[17]	USA	Prospective, longitudinal study on QoL in patients before and after kidney transplant	33	Baseline, 6 and 12 months	▲ Interviews ▲ ▲ QoL rating scale ▲ ▲ Measurement of physical and mental health functioning	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.
Damsgaard *et al*, 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	Semistructured interviews and observations	Despite most patients being largely pain-free after surgery; sadness returned in several patients.
Lee *et al*, 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	Surveys based on: ▲ Cantril Ladder for happiness ▲ ▲ Breast-Q Satisfaction with Decisions and Decision Regret Scale ▲ For QoL numeric rating scale of 0–100	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))

QoL, quality of life.

Table 2 Between-subject design

Source, year	Country	Population studied	Sample size	Methods of measurement	Conclusion
Riis *et al*, 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	► 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 *et al*, 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	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 *et al*, 2009 (Part 2)[17]	USA	Patients waiting for kidney transplant compared with patients after kidney transplant	307	► 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 *et al*, 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	► 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 *et al*, 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	► 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 reprioritisation 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 live 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.

Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests None declared.

Patient consent for publication Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available on reasonable request. The datasets used and analysed during the current study are available from the corresponding author on reasonable request.

ORCID iDs

G J van den Bosch http://orcid.org/0000-0002-7108-2934

Claudi Bockting http://orcid.org/0000-0002-9220-9244

REFERENCES

1 Hsee CK, Hastie R. Decision and experience: why don't we choose what makes us happy? *Trends Cogn Sci* 2006;10:31–7.
2 Wilson TD, Gilbert DT. Affective forecasting. *Adv Exp Soc Psychol* 2003;35:345–411.
3 Gilbert DT, Pinel EC, Wilson TD, *et al*. Immune neglect: a source of durability bias in affective forecasting. *J Pers Soc Psychol* 1998;75:617–38.
4 Albrecht GL, Devlieger PJ. The disability paradox: high quality of life against all odds. *Soc Sci Med* 1999;48:977–88.
5 Lench HC, Safer MA, Levine LJ. Focalism and the underestimation of future emotion: when it's worse than imagined. *Emotion* 2011;11:278–85.
6 Balestroni G, Bertolotti G. L'EuroQol-5D (EQ-5D): uno strumento per la misura della qualit della vita [EuroQol-5D (EQ-5D): an instrument for measuring quality of life]. *Monaldi Arch Chest Dis* 2012;78:155–9.
7 Cantril H. *The pattern of human concerns*. New Brunswick, N.J: Rutgers University Press, 1967.
8 Burckhardt CS, Anderson KL. The quality of life scale (QOLS): reliability, validity, and utilization. *Health Qual Life Outcomes* 2003;1:60.
9 Buechel EC, Zhang J, Morewedge CK. Impact bias or underestimation? outcome specifications predict the direction of affective forecasting errors. *J Exp Psychol Gen* 2017;146:746–61.
10 Bjälkebring P, Västfjäll D, Svenson O, *et al*. Regulation of experienced and anticipated regret in daily decision making. *Emotion* 2016;16:381–6.
11 Finkenauer C, Gallucci M, van Dijk WW, *et al*. Investigating the role of time in affective forecasting: temporal influences on forecasting accuracy. *Pers Soc Psychol Bull* 2007;33:1152–66.
12 Kopp L, Atance CM, Pearce S. 'Things aren't so bad!': Preschoolers overpredict the emotional intensity of negative outcomes. *Br J Dev Psychol* 2017;35:623–7.
13 Gautam S, Bulley A, von Hippel W, *et al*. Affective forecasting bias in preschool children. *J Exp Child Psychol* 2017;159:175–84.
14 Van Dijk WW. How do you feel? affective forecasting and the impact bias in track athletics. *J Soc Psychol* 2009;149:343–8.
15 Ouzzani M, Hammady H, Fedorowicz Z, *et al*. Rayyan-a web and mobile APP for systematic reviews. *Syst Rev* 2016;5:210.
16 Liberati A, Altman DG, Tetzlaff J, *et al*. The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate health care interventions: explanation and elaboration. *J Clin Epidemiol* 2009;62:e1–34.
17 Smith D, Loewenstein G, Jepson C, *et al*. Mispredicting and misremembering: patients with renal failure overestimate improvements in quality of life after a kidney transplant. *Health Psychol* 2008;27:653–8.
18 Damsgaard JB, Jørgensen LB, Norlyk A, *et al*. Spinal fusion surgery: from relief to insecurity. *Int J Orthop Trauma Nurs* 2017;24:31–9.
19 Lee CN-H, Pignone MP, Deal AM, *et al*. Accuracy of predictions of patients with breast cancer of future well-being after immediate breast reconstruction. *JAMA Surg* 2018;153:e176112.
20 Smith DM, Sherriff RL, Damschroder L, *et al*. Misremembering colostomies? former patients give lower utility ratings than do current patients. *Health Psychol* 2006;25:688–95.
21 Levine LJ, Lench HC, Kaplan RL, *et al*. Like Schrödinger's cat, the impact bias is both dead and alive: reply to Wilson and Gilbert (2013). *J Pers Soc Psychol* 2013;105:749–56.
22 Cheng Q, He G. Deciding for future selves reduces loss aversion. *Front Psychol* 2017;8:1644.
23 Buran CF, Sawin KJ, Brei TJ, *et al*. Adolescents with myelomeningocele: activities, beliefs, expectations, and perceptions. *Dev Med Child Neurol* 2004;46:244–52.
24 Adang EM, Kootstra G, Engel GL, *et al*. Do retrospective and prospective quality of life assessments differ for pancreas-kidney transplant recipients? *Transpl Int* 1998;11:11–15.
25 Thompson RJ, Spectre A, Insel PS. Positive and negative affective forecasting in Remitted individuals with bipolar I disorder, and Marjor depressive disorder, and healthy controls. *Cogn Ther Res* 2017.
26 Brenner CJ, Ben-Zeev D. Affective forecasting in schizophrenia: comparing predictions to real-time ecological Momentary assessment (EMA) ratings. *Psychiatr Rehabil J* 2014;37:316–20.
27 Hoerger M, Quirk SW, Chapman BP, *et al*. Affective forecasting and self-rated symptoms of depression, anxiety, and hypomania: evidence for a dysphoric forecasting bias. *Cogn Emot* 2012;26:1098–106.

28 Halpern J, Arnold RM. Affective forecasting: an unrecognized challenge in making serious health decisions. *J Gen Intern Med* 2008;23:1708–12.
29 Ilie G, Bradfield J, Moodie L, *et al*. The role of Response-Shift in studies assessing quality of life outcomes among cancer patients: a systematic review. *Front Oncol* 2019;9:783.
30 Hirakawa Y, Chiang C, Hilawe EH, *et al*. Content of advance care planning among Japanese elderly people living at home: a qualitative study. *Arch Gerontol Geriatr* 2017;70:162–8.
31 Schenker Y, White DB, Arnold RM. What should be the goal of advance care planning? *JAMA Intern Med* 2014;174:1093–4.
32 Heyland DK, Heyland R, Dodek P, *et al*. Discordance between patients' stated values and treatment preferences for end-of-life care: results of a multicentre survey. *BMJ Support Palliat Care* 2017;7:292–9.
33 Riis J, Loewenstein G, Baron J, *et al*. Ignorance of hedonic adaptation to hemodialysis: a study using ecological momentary assessment. *J Exp Psychol Gen* 2005;134:3–9.
34 Peeters Y, Vliet Vlieland TPM, Stiggelbout AM. Focusing illusion, adaptation and EQ-5D health state descriptions: the difference between patients and public. *Health Expect* 2012;15:367–78.
35 Goranson A, Ritter RS, Waytz A, *et al*. Dying is unexpectedly positive. *Psychol Sci* 2017;28:988–99.

Appendix 1.1 Search strategy in PubMed (2021 April 12th)

#	Query	Results
#6	#1 OR #5	**1,856**
#5	#2 AND #3 AND #4	**1,744**
#4	"Clinical Decision-Making"[Mesh] OR "Decision Making"[Mesh] OR "decision making*"[tiab]	**324,699**
#3	"Emotions"[MeSH] OR emotions[tiab] OR feelings[tiab]	**298,360**
#2	"Forecasting"[Mesh] OR forecasting[tiab] OR predicting[tiab] OR prediction[tiab] OR future[tiab]	**1,336,974**
#1	"affective forecast*"[tiab] OR "impact bias"[tiab]	**135**

Appendix 1.2 Embase.com Session Results (2021 April 12th)

#	Query	Results
#6	#1 OR #5	**4,035**
#5	#2 AND #3 AND #4	**3,911**
#4	'clinical decision making'/de OR 'decision making'/de OR 'medical decision making'/exp OR 'patient decision making'/exp OR 'shared decision making'/exp OR 'decision making':ti,ab,kw	**463,396**
#3	'emotion'/exp OR emotions:ti,ab,kw OR feelings:ti,ab,kw	**686,673**
#2	'prediction and forecasting'/de OR 'forecasting'/exp OR 'prediction'/exp OR 'predictive validity'/exp OR prediction:ti,ab,kw OR predicting:ti,ab,kw OR forecasting:ti,ab,kw OR future:ti,ab,kw	**1,945,306**

#1	'affective forecast*':ti,ab,kw OR 'impact bias':ti,ab,kw	**152**

Appendix 1.3 CINAHL (Ebsco) Session Results (2021 April 12th)

#	Query	Results
S6	S1 OR S5	**906**
S5	S2 AND S3 AND S4	**863**
S4	MH "Decision Making, Clinical" OR MH "Decision Making+" OR TI "decision making*" OR AB "decision making*"	**165,163**
S3	MH "Emotions+" OR TI (emotions OR feelings) OR AB (emotions OR feelings)	**184,287**
S2	MH "Forecasting" OR TI (forecasting OR predicting OR prediction OR future) OR AB (forecasting OR predicting OR prediction OR future)	**348,464**
S1	TI ("affective forecast*" OR "impact bias") OR AB ("affective forecast*" OR "impact bias")	**51**

Appendix 1.4 Cochrane Library (Wiley) Session Results (2021 April 12th)

#	Query	Results
#6	#1 or #5	**59**
#5	#2 and #3 and #4	**48**
#4	(decision NEXT making):ti,ab,kw	**14,116**
#3	emotions:ti,ab,kw or feelings:ti,ab,kw	**10,820**

#2	prediction:ti,ab,kw or predicting:ti,ab,kw or forecasting:ti,ab,kw or future:ti,ab,kw	**65,831**
#1	((affective NEXT forecast*) or (impact NEXT bias)):ti,ab,kw	**11**

APPENDIX 2: QUALITY CRITERIA CHECKLIST

Legenda:

Ran Roos

G Bosch

Smith, D. Loewenstein, G. Jepson, C. Jankovich, A. Feldman, H. Ubel, P. Mispredicting and Misremembering: Patients With Renal Failure Overestimate Improvements in Quality of Life After a Kidney Transplant. Health Psychology 2008, Vol. 27, No. 5, 653-658

National Heart, Lung, and Blood Institute, Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies

Criteria	Yes	No	Other (CD, NR, NA)*
1. Was the research question or objective in this paper clearly stated?	X		
2. Was the study population clearly specified and defined?	X		
3. Was the participation rate of eligible persons at least 50%?	X		
4. Were all the subjects selected or recruited from the same or similar populations (including the same time period)? Were inclusion and exclusion criteria for being in the study prespecified and applied uniformly to all participants?	X	X	
5. Was a sample size justification, power description, or variance and effect estimates provided?		X	
6. For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?	X		
7. Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed?	X		

Criteria	Yes	No	Other (CD, NR, NA)*
8. For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome (e.g., categories of exposure, or exposure measured as continuous variable)?			NA
9. Were the exposure measures (independent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?	X		
10. Was the exposure(s) assessed more than once over time?	X		
11. Were the outcome measures (dependent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?	X		
12. Were the outcome assessors blinded to the exposure status of participants?			NA
13. Was loss to follow-up after baseline 20% or less?		X	
14. Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?	X		

Quality Rating (Good, Fair, or Poor)
Rater #1 initials: RAN ROOS: **predominantly GOOD**
Rater #2 initials: G BOSCH: **predominantly GOOD**
Additional Comments (If POOR, please state why):

Damsgaard, J.B. Jorgensen, L.B. Norlyk, A. Birkelund, R. Spinal fusion surgery: From relief to insecurity. International Journal of Orthopaedic and Trauma Nursing (2016). Doi: 10.1016/j/ijotn.2016.06.001

Quality assessment for the systematic review of qualitative evidence op basis van Hawker S, Payne S, Kerr C, Hardey M, Powell J. Appraising the evidence: reviewing disparate data systematically. Qual Health Res 2002;12:1284–99. 10.1177/1049732302238251.

1. *Abstract and title*. Did they provide a clear description of the study?

   Good: structured abstract with full information and clear title. Fair: abstract with most of the information. Poor: inadequate abstract. Very poor: no abstract.

   Good

2. *Introduction and aims*. Was there a good background section and clear statement of the aims of the research?

   Good: full but concise background to discussion/study containing up-to-date literature review and highlighting gaps in knowledge; clear statement of aim AND objectives including research questions. Fair: some background and literature review; research questions outlined. Poor: some background but no aim/objectives/questions OR aims/objectives but inadequate background. Very poor: no mention of aims/objectives; no background or literature review.

   Ran Roos: Good

   G Bosch: Fair (no objectives including research questions)

3. *Method and data*. Is the method appropriate and clearly explained?

   Good: method is appropriate and described clearly (e.g. questionnaires included); clear details of the data collection and recording. Fair: method appropriate, description could be better; data described. Poor: questionable whether method is appropriate; method described inadequately; little description of data. Very poor: no mention of method AND/OR method inappropriate AND/OR no details of data.

   Fair

4. *Sampling*. Was the sampling strategy appropriate to address the aims?

   Good: details (age/gender/race/context) of who was studied and how they were recruited and why this group was targeted; the sample size was justified for the study; response rates shown and explained. Fair: sample size justified; most information given but some missing. Poor: sampling mentioned but few descriptive details. Very poor: no details of sample.

   Ran Roos: Fair (small sample size)

   G Bosch: fair (small sample size, some information missing (oa time onset disease)

5. *Data analysis*. Was the description of the data analysis sufficiently rigorous?

   Good: clear description of how analysis was carried out; description of how themes derived/respondent validation or triangulation. Fair: descriptive discussion of analysis. Poor: minimal details about analysis. Very poor: no discussion of analysis.

   Fair

6. *Ethics and bias*. Have ethical issues been addressed and has necessary ethical approval been gained?Has the relationship between researchers and participants been adequately considered?

Good: ethics: when necessary, issues of confidentiality, sensitivity and consent were addressed; bias: researcher was reflexive and/or aware of own bias. Fair: lip service was paid to above (i.e. these issues were acknowledged). Poor: brief mention of issues. Very poor: no mention of issues.

Good

7. *Results*. Is there a clear statement of the findings?

   Good: findings explicit, easy to understand and in logical progression; tables, if present, are explained in text; results relate directly to aims; sufficient data are presented to support findings. Fair: findings mentioned but more explanation could be given; data presented relate directly to results. Poor: findings presented haphazardly, not explained and do not progress logically from results. Very poor: findings not mentioned or do not relate to aims.

   Fair (more explanation could be given)

8. *Transferability or generalisability*. Are the findings of this study transferable (generalisable) to a wider population?

   Good: context and setting of the study are described sufficiently to allow comparison with other contexts and settings, plus high score in Q4 (sampling). Fair: some context and setting described but more needed to replicate or compare the study with others, plus fair score or higher in Q4. Poor: minimal description of context/setting. Very poor: no description of context/setting.

   Ran Roos: Good

   G Bosch: Fair

9. *Implications and usefulness*. How important are these findings to policy and practice?

   Good: contributes something new and/or different in terms of understanding/insight or perspective; suggests ideas for further research; suggests implications for policy and/or practice. Fair: two of the above. Poor: only one of the above. Very poor: none of the above.

   Fair

RAN ROOS: Fair

G BOSCH: Fair

Nan-hi Lee, C. Pignone, M.P. Deal, A.M. Blizard, L. Hunt, C. Huh, R. Liu, Y-J. Ubel, P.A. Accuracy of Predictions of Patients With Breast Cancer of Future Well-being AFter Immediate Breast Reconstruction. *JAMA Surg.* 2018 Apr;153(4):e176112.

Criteria	Yes	No	Other (CD, NR, NA)*
1. Was the research question or objective in this paper clearly stated?	X		
2. Was the study population clearly specified and defined?	X		
3. Was the participation rate of eligible persons at least 50%?	X		
4. Were all the subjects selected or recruited from the same or similar populations (including the same time period)? Were inclusion and exclusion criteria for being in the study prespecified and applied uniformly to all participants?	X		
5. Was a sample size justification, power description, or variance and effect estimates provided?	X		
6. For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?	X		
7. Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed?	X		

Criteria	Yes	No	Other (CD, NR, NA)*
8. For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome (e.g., categories of exposure, or exposure measured as continuous variable)?	X		
9. Were the exposure measures (independent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?	X		
10. Was the exposure(s) assessed more than once over time?	X		
11. Were the outcome measures (dependent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?	X		
12. Were the outcome assessors blinded to the exposure status of participants?		X	
13. Was loss to follow-up after baseline 20% or less?	X		
14. Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?	X		

Quality Rating (Good, Fair, or Poor)
Rater #1 initials: ROOS RAN: **GOOD**
Rater #2 initials: G BOSCH: **GOOD**
Additional Comments (If POOR, please state why):

Riis, J. Baron, J. Loewenstein, G. Jepson, C.: Ignorance of Hedonic Adaptation to Hemodialysis: A Study Using Ecological Momentary Assessment. Journal of Experimental Psychology: General 2005, Vol. 134, No. 1, 3-9

Criteria	Yes	No	Other (CD, NR, NA)*
1. Was the research question or objective in this paper clearly stated?	X	X	
2. Was the study population clearly specified and defined?	X		
3. Was the participation rate of eligible persons at least 50%?		X	
4. Were all the subjects selected or recruited from the same or similar populations (including the same time period)? Were inclusion and exclusion criteria for being in the study prespecified and applied uniformly to all participants?	X		
5. Was a sample size justification, power description, or variance and effect estimates provided?		X	
6. For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?	X		
7. Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed?		X	

Criteria	Yes	No	Other (CD, NR, NA)*
8. For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome (e.g., categories of exposure, or exposure measured as continuous variable)?	X		
9. Were the exposure measures (independent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?	X		
10. Was the exposure(s) assessed more than once over time?	X		
11. Were the outcome measures (dependent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?		X	
12. Were the outcome assessors blinded to the exposure status of participants?		X	
13. Was loss to follow-up after baseline 20% or less?	X		
14. Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?		X	

Quality Rating (Good, Fair, or Poor)
Rater #1 initials: RAN ROOS: **FAIR**
Rater #2 initials: G BOSCH: **FAIR**
Additional Comments (If POOR, please state why):

Smith, D.M. Damschroder, L. Sherriff, R.L. Loewenstein, G. Misremembering Colostomies? Former Patients Give Lower Utility Ratings Than Do Current Patients. Health Psychology 2006, Vol. 25, No. 6, 688-695.

Criteria	Yes	No	Other (CD, NR, NA)*
1. Was the research question or objective in this paper clearly stated?	X		
2. Was the study population clearly specified and defined?	X		
3. Was the participation rate of eligible persons at least 50%?		X	
4. Were all the subjects selected or recruited from the same or similar populations (including the same time period)? Were inclusion and exclusion criteria for being in the study prespecified and applied uniformly to all participants?	X	X	
5. Was a sample size justification, power description, or variance and effect estimates provided?		X	
6. For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?	X		
7. Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed?	X		

Criteria	Yes	No	Other (CD, NR, NA)*
8. For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome (e.g., categories of exposure, or exposure measured as continuous variable)?	X		
9. Were the exposure measures (independent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?	X		
10. Was the exposure(s) assessed more than once over time?		X	
11. Were the outcome measures (dependent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?	X		
12. Were the outcome assessors blinded to the exposure status of participants?		X	
13. Was loss to follow-up after baseline 20% or less?			NA
14. Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?	X		

Quality Rating (Good, Fair, or Poor)
Rater #1 initials: RAN ROOS: **FAIR**
Rater #2 initials: G BOSCH: **FAIR**
Additional Comments (If POOR, please state why):

Peeters, Y. Vliet Vlieland, T.P.M. Stiggelbout, A.M. Focusing illusion, adaptation and EQ-5D health state descriptions: the difference between patients and public. Health Expectations, 15, pp.367-378. DOI:10.1111/j.1369-7625.2011.00667.x

Quality assessment for the systematic review of qualitative evidence op basis van Hawker S, Payne S, Kerr C, Hardey M, Powell J. Appraising the evidence: reviewing disparate data systematically. Qual Health Res 2002;12:1284–99. 10.1177/1049732302238251.

1. *Abstract and title*. Did they provide a clear description of the study?

   Good: structured abstract with full information and clear title. Fair: abstract with most of the information. Poor: inadequate abstract. Very poor: no abstract.

   GOOD

2. *Introduction and aims*. Was there a good background section and clear statement of the aims of the research?

   Good: full but concise background to discussion/study containing up-to-date literature review and highlighting gaps in knowledge; clear statement of aim AND objectives including research questions. Fair: some background and literature review; research questions outlined. Poor: some background but no aim/objectives/questions OR aims/objectives but inadequate background. Very poor: no mention of aims/objectives; no background or literature review.

   GOOD

   G Bosch: FAIR (research questions stated clearly in methods, but not in introductions)

3. *Method and data*. Is the method appropriate and clearly explained?

   Good: method is appropriate and described clearly (e.g. questionnaires included); clear details of the data collection and recording. Fair: method appropriate, description could be better; data described. Poor: questionable whether method is appropriate; method described inadequately; little description of data. Very poor: no mention of method AND/OR method inappropriate AND/OR no details of data.

   GOOD

4. *Sampling*. Was the sampling strategy appropriate to address the aims?

   Good: details (age/gender/race/context) of who was studied and how they were recruited and why this group was targeted; the sample size was justified for the study; response rates shown and explained. Fair: sample size justified; most information given but some missing. Poor: sampling mentioned but few descriptive details. Very poor: no details of sample.

   FAIR (why patients with RA?)

5. *Data analysis*. Was the description of the data analysis sufficiently rigorous?

   Good: clear description of how analysis was carried out; description of how themes derived/respondent validation or triangulation. Fair: descriptive discussion of analysis. Poor: minimal details about analysis. Very poor: no discussion of analysis.

   FAIR

6. *Ethics and bias*. Have ethical issues been addressed and has necessary ethical approval been gained?Has the relationship between researchers and participants been adequately considered?

Good: ethics: when necessary, issues of confidentiality, sensitivity and consent were addressed; bias: researcher was reflexive and/or aware of own bias. Fair: lip service was paid to above (i.e. these issues were acknowledged). Poor: brief mention of issues. Very poor: no mention of issues.

FAIR

7. *Results*. Is there a clear statement of the findings?

   Good: findings explicit, easy to understand and in logical progression; tables, if present, are explained in text; results relate directly to aims; sufficient data are presented to support findings. Fair: findings mentioned but more explanation could be given; data presented relate directly to results. Poor: findings presented haphazardly, not explained and do not progress logically from results. Very poor: findings not mentioned or do not relate to aims.

   RAN ROOS: GOOD

   G BOSCH: FAIR (more explanation needed on the relation between EQ-5D and self-named aspects + ranking of EQ-5D aspects)

8. *Transferability or generalisability*. Are the findings of this study transferable (generalisable) to a wider population?

   Good: context and setting of the study are described sufficiently to allow comparison with other contexts and settings, plus high score in Q4 (sampling). Fair: some context and setting described but more needed to replicate or compare the study with others, plus fair score or higher in Q4. Poor: minimal description of context/setting. Very poor: no description of context/setting.

   GOOD

9. *Implications and usefulness*. How important are these findings to policy and practice?

   Good: contributes something new and/or different in terms of understanding/insight or perspective; suggests ideas for further research; suggests implications for policy and/or practice. Fair: two of the above. Poor: only one of the above. Very poor: none of the above.

   FAIR

RAN ROOS: FAIR

G BOSCH: **FAIR**

Goranson, A. Ritter, R.S. Waytz, A. Norton, M.I. Gray, K. Dying is Unexpectedly Positive. Psychological Science 2017, Vol. 28(7) 988-999 (Study I)

Quality assessment for the systematic review of qualitative evidence op basis van Hawker S, Payne S, Kerr C, Hardey M, Powell J. Appraising the evidence: reviewing disparate data systematically. Qual Health Res 2002;12:1284–99. 10.1177/1049732302238251.

1. *Abstract and title*. Did they provide a clear description of the study?

   Good: structured abstract with full information and clear title. Fair: abstract with most of the information. Poor: inadequate abstract. Very poor: no abstract.

   FAIR (no information about sampling, method i.e.)

2. *Introduction and aims*. Was there a good background section and clear statement of the aims of the research?

   Good: full but concise background to discussion/study containing up-to-date literature review and highlighting gaps in knowledge; clear statement of aim AND objectives including research questions. Fair: some background and literature review; research questions outlined. Poor: some background but no aim/objectives/questions OR aims/objectives but inadequate background. Very poor: no mention of aims/objectives; no background or literature review.

   FAIR (no clear research questions /objectives)

3. *Method and data*. Is the method appropriate and clearly explained?

   Good: method is appropriate and described clearly (e.g. questionnaires included); clear details of the data collection and recording. Fair: method appropriate, description could be better; data described. Poor: questionable whether method is appropriate; method described inadequately; little description of data. Very poor: no mention of method AND/OR method inappropriate AND/OR no details of data.

   FAIR

4. *Sampling*. Was the sampling strategy appropriate to address the aims?

   Good: details (age/gender/race/context) of who was studied and how they were recruited and why this group was targeted; the sample size was justified for the study; response rates shown and explained. Fair: sample size justified; most information given but some missing. Poor: sampling mentioned but few descriptive details. Very poor: no details of sample.

   FAIR

5. *Data analysis*. Was the description of the data analysis sufficiently rigorous?

   Good: clear description of how analysis was carried out; description of how themes derived/respondent validation or triangulation. Fair: descriptive discussion of analysis. Poor: minimal details about analysis. Very poor: no discussion of analysis.

   FAIR

6. *Ethics and bias*. Have ethical issues been addressed and has necessary ethical approval been gained?Has the relationship between researchers and participants been adequately considered?

   Good: ethics: when necessary, issues of confidentiality, sensitivity and consent were addressed; bias: researcher was reflexive and/or aware of own bias. Fair: lip service was paid

to above (i.e. these issues were acknowledged). Poor: brief mention of issues. Very poor: no mention of issues.

POOR

7. *Results*. Is there a clear statement of the findings?

   Good: findings explicit, easy to understand and in logical progression; tables, if present, are explained in text; results relate directly to aims; sufficient data are presented to support findings. Fair: findings mentioned but more explanation could be given; data presented relate directly to results. Poor: findings presented haphazardly, not explained and do not progress logically from results. Very poor: findings not mentioned or do not relate to aims.

   GOOD

8. *Transferability or generalisability*. Are the findings of this study transferable (generalisable) to a wider population?

   Good: context and setting of the study are described sufficiently to allow comparison with other contexts and settings, plus high score in Q4 (sampling). Fair: some context and setting described but more needed to replicate or compare the study with others, plus fair score or higher in Q4. Poor: minimal description of context/setting. Very poor: no description of context/setting.

   FAIR

9. *Implications and usefulness*. How important are these findings to policy and practice?

   Good: contributes something new and/or different in terms of understanding/insight or perspective; suggests ideas for further research; suggests implications for policy and/or practice. Fair: two of the above. Poor: only one of the above. Very poor: none of the above.

   FAIR

RAN ROOS: FAIR

G BOSCH: FAIR

Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	Main text, page 1; title
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	Main text page 2; abstract
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	Main text page 5; introduction
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	Main text page 6; last part introduction
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	Main text page 13; declarations
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	Main text page 6-7; selection criteria
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	Main text page 6; search strategy
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	Appendix 1.1-1.4
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	Main text page 7; data extraction
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	Main text page 7; data extraction
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	Main text page 6; search strategy

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	Not applicable
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	Main text page 7; data extraction
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	Main text page 7; results, figure 1
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	Main text page 8-9; table 1 and table 2
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	Not applicable
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	Main text page 8-9; table 1 and table 2
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	Main text page 8-9
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	Main text page 10-11; first part discussion
Limitations	20	Discuss the limitations of the scoping review process.	Main text page 11-12; limitations
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	Main text page 12-13; clinical implications and conclusion
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	Main text page 13; declarations

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMAScR): Checklist and Explanation. Ann Intern Med. 2018;169:467–473. doi: 10.7326/M18-0850.