The bias of adapted patients in practice

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I. INTRODUCTION

Often, the self-reported utility of the health-states of patients clashes with the judgement that the general public has of the same health-states. The general public tends to judge certain conditions more negatively than those who live with these conditions. There is evidence that some patients with a certain disability, disease, or patients receiving a certain treatment, judge their state more positively after several years living with that condition, disease, or treatment. This phenomenon, known as ‘adaptation’, poses a challenge to priority-setting in the context of health care allocation.

In this context, when the judgements of the patients and the public diverge, it is crucial to find out whose judgements and preferences should be trusted since health-state utility assessments inform resource allocation. Given the possibility that patients’ self-reported scores respond to a biased judgement of their current health-state, should patients’ self-reported utility be disregarded? If so, whose judgements should be trusted instead? This is a relevant question in the context of health care priority setting where priority should be allocated according to how patients really fare, with the aim of promoting their medical interests.

In his chapter “Measuring Health-State Utility via Cured Patients”, Nir Eyal puts forward a proposal aimed at solving this issue. His measure of health-state utility relies on the self-reported utility of current patients but combines it with the utility that former patients (ie patients who have had the same condition or have undergone the same treatment but have eventually recovered from it) ascribe to those same states, giving higher weight to the judgements of former patients. Eyal’s proposal is conceived as an alternative to the measures commonly used by most health care systems, which tend to give priority either to the judgements of the general public (as practiced in the

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1 Nir Eyal, Measuring Health-State Utility via Cured Patients, in Disability, Health, Law, and Bioethics, (I. Glenn Cohen, Carmel Shachar, Anita Silvers, Michael Ashley Stein, eds.) 274–277 (2020).
Netherlands, UK, and USA) or to the judgements of the current patients (as practiced in northern European countries, and which has become more favored by researchers lately).

The paper proceeds as follows. In section 2, I review the motivation behind Eyal’s proposal. In section 3, I raise some counterintuitive results that follow from the functioning of the formula that Eyal uses to adjust patients’ scores and I elaborate on the possible sources of these results. In section 4, I discuss the rationale behind the use of average scores and refer to the importance of considering the distribution of the data coming out of patients’ scores surveys, which may vary by condition. Section 5 is the conclusion.

II. BAP AND THE EPISTEMIC ACCESS OF FORMER PATIENTS

Current patients with a certain condition, or patients who have been under a certain treatment for some time, tend to judge their condition more positively than the public. Evidence suggests that this responds to the fact that patients tend to evaluate their conditions more positively the more time they live with that condition.

Different explanations have been provided as to why such adaptation to a condition or a treatment occurs. On one hand, adaptation might respond to skill enhancement, a change in activity for the achievement of a same goal, or the acquisition of a less stigmatizing view about that particular health state. In such cases, adapted patients’ less negative judgements would seem more informed, reasonable, reliable, and unproblematic, compared to the public’s. On the other hand, adaptation might instead respond to cognitive denial, to having forgotten what being in full health enables one to do, to a (more or less) abrupt change in personal tastes and judgements about final ends with the purpose of avoiding disappointment (what is known as the ‘sour grapes phenomenon’), or simply to reporting biases. In such cases, reliance on patients’ less negative judgements about their health states is less favorable.

It is the latter form of ‘adaptation’ that casts doubt on the reliability of current patients’ self-reported utility assessments. If adaptation is a response to some sort of wishful thinking about one’s health state, the utility that current patients report about their health state would seem to be biased and therefore not a precise representation of patients’ ‘real’ utility, which would lead to the wrong prioritization (eg underproviding for that patient). Since the aim of the health care system is to promote the medical interests of its patients, it is crucial that it can get as close as possible to the real utility values of its patients.

There has been a lively debate on adaptation in the medical, disability, and philosophical literature in recent years. A great deal of attention has been paid to whether adapted preferences should be seen as irrational. Such evaluation has been criticized by some philosophers of disability. Some have suggested that treating adapted preferences as irrational undermines the credibility of current patients which, some claim, constitutes a case of testimonial or epistemic injustice. Others have suggested that while

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2 Juha Räikkä and Jukka Varelius (eds), Adaptation and Autonomy: Adaptive Preferences in Enhancing and Ending Life (2013).
3 Elizabeth Barnes, Disability and Adaptive Preference, 23 Philosophical Perspectives 1–22 (2009).
4 Elizabeth Barnes, Disability, Minority, and Difference, 26 Journal of Applied Philosophy 337–355 (2009).
5 Elizabeth Barnes, The Minority Body: A Theory of Disability (2016).
some preferences might be adaptive and therefore not trustworthy in the context of distributive justice, this does not imply that the individuals who hold these preferences should be seen as irrational.\footnote{Jessica Begon, What Are Adaptive Preferences? Exclusion and Disability in the Capability Approach, 32 JOURNAL OF APPLIED PHILOSOPHY 241–257 (2014).} I take the concern about adaptation raised by Eyal to be consistent with this latter position.

The possibility that current patients’ reports are biased undermines the credibility of these patients as a source of evidence for the utility of their health-states, at least to the extent that their reports are an ‘insufficient’ source of evidence. Thus, consulting additional sources of evidence seems like a good alternative strategy.

Eyal chooses this route. He proposes to complement current patients’ reports with the reports of former patients (ie patients who have had the same condition or have undergone the same treatment but have eventually recovered from it). I take the motivation for this choice to be that former patients possess a privileged epistemic position over current patients when it comes to judging the condition or treatment. Former patients have greater epistemic access in the sense that they have access to the health state prior to having that condition and to the health state after having recovered from the condition, and so can make an informed comparison of the condition to both their prior and posterior health states. This enables them to make richer comparisons than the comparison that current patients would be able to make, given that the set of health states that current patients can access and compare their condition against is smaller than the set of health states of recovered patients.

Provided that the patient stays in a health condition for a sufficiently long period of time that enables her to experience this condition to a sufficient extent, having alternated health stages (healthy-patient-cured) would seem to provide a better grasp of the states.\footnote{I take the bias of adapted patients introduced by Eyal to occur after a sufficiently long period of time with a condition. This time may vary depending on the condition. It is likely that patients will evaluate their condition significantly lower just after they have acquired their condition.} However, since there are other biases that former patients’ judgements may also be subject to,\footnote{Supra note 1.} their judgements are meant to serve only as an adjustment of current patients’ scores.\footnote{One may want to press further on what Eyal’s measure is supposed to track. A possible answer would be medical interests, which can be understood as equivalent to wellbeing. But if wellbeing is subjective, then former patients’ judgements need not be seen as privileged, even if former patients have experienced both health states. The temporal distance between your current self and your past experience may make you an imperfect judge of the subjective wellbeing of your past self (See Henry Sidgwick, The Methods of Ethics (Cambridge Library Collection - Philosophy) (2011)). Although relevant, I will not pursue this line of argument here and will assume (for the sake of the argument) that the relevant notion of welfare here is objective.} 9, 10

Eyal’s proposal is offered as an approach to evaluating health states for the allocation of scarce health care resources. In this context, distributors need to make decisions about which patients should be given medical priority, without having first-hand experience of what it is like to have those conditions, and with patients’ reports that seem...
to respond to biases. This is a challenging setting. If certain conditions or disabilities change the preferences of the person with such condition in a significant way, then both the appeal to the general public’s judgements and the appeal to the patient’s judgements alone are problematic. According to this view, appealing to the judgements of the general public would be a mistake since the general public is the candidate with the least epistemic access to the condition whose utility is being evaluated, given that the people in the general public have not experienced that condition themselves. And although current patients are better positioned than the general public given that they have direct epistemic access to the condition under evaluation, their judgement might respond to a profound change in preferences like the one produced under the phenomenon of adaptation. This is the challenge Eyal’s measure responds to.

A crucial aspect of the measure proposed by Eyal is the different weights that it assigns to its elements, namely the judgements of current patients, the judgements of former patients, and the judgement of the particular patient whose health state is under evaluation. In the next section, I show how the distribution of weights across these three elements makes a significant difference in the evaluation of the utility of different patients’ health states. I also show how the measure gives some counterintuitive results in certain kinds of cases.

III. THE MEASURE

Eyal proposes to adjust current patients’ reported scores with the purpose of arriving to a more realistic or non-biased evaluation of their health states. The ultimate goal is to determine how important it is to prevent, treat, cure, or mitigate a condition, when doing so conflicts with attending to the needs of other patients.

The score of patients with a condition is adjusted by the Bias of Adapted Patients (BAP) for that condition. BAP is a function of the scores that former and current patients give for that particular condition (X) and it is calculated by dividing the average of the scores that current patients report (Average of Current Patients’ Score, or ACPS) by the average of the scores that former patients report (Average of Former Patients’ Score, or AFPS).

$$\text{BAP for } X = \frac{\text{ACPS for } X}{\text{AFPS for } X}$$

BAP is used to adjust the score of patients whose real utility ought to be evaluated. For simplicity, in what follows I will refer to this score as the Test Patient’s Score, or TPS. While Eyal seems to conceive of BAP as an adjuster of group scores, it is possible to use BAP to adjust individual scores. And while there is an important difference between the disvalue of paraplegia as a whole and the disvalue of paraplegia for me, whether the score is a representation of individual or group values is in principle irrelevant for

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11 For a thorough elaboration on different alternative approaches to the measurement of health, see Daniel M. Hausman, Valuing Health: Well-Being, Freedom, and Suffering (2015).
12 Supra note 1, at 267.
13 Or for conditions of the same kind, or that are similar enough, in cases in which the BAP of that condition is not available (Supra note 1, at 271–274.).
14 Supra note 1, at 270–271.
15 In private communication with Eyal (Mar. 20, 2020).
the structural issues that will be raised below regarding the strict functioning of the measure.¹⁶

Now, the adjustment of a given patient’s score (or a group score) by BAP is done by dividing TPS by the BAP score for that condition. The lower the final, adjusted score, the higher medical priority should be given to that condition.

\[
TPS \text{ adjusted by BAP} = \frac{TPS}{BAP} = \left(\frac{ACPS}{AFPS}\right)
\]

Something to notice is that by adjusting a score by BAP, it would seem like significantly greater weight is given to the judgement of former patients, greater than to the judgment of current patients, and greater than to the judgement of the patient whose utility is under ascertainment. This is precisely what Eyal intends. The partial discount of the judgement of current patients is meant as a way to neutralize the patient’s adaptation bias. Below I show that the role that the former and current patient’s scores play is actually more complicated than this.

Although the greater weight that seems to be given to the judgement of former patients is intentional, the way in which the measure incorporates this weight leads to a significant bias in favor of the judgement of former patients, which in certain cases results in odd and counterintuitive prioritization recommendations. In some cases, when comparing the scores of two patients (after being adjusted by BAP), the resulting recommendation is to give medical priority to the patient with the condition that on average is rated with higher utility by former patients and current patients with that same condition, as well as by the particular patient whose health state is under evaluation, over another patient whose condition is rated with lower utility by those same three evaluators.

Below is a simplified case, Case 1, where BAP is applied to the reported scores of two patients, \(x\) and \(y\), with two different medical conditions, disabilities, or treatments, \(X\) and \(Y\), respectively:

**Case 1. Comparison between the utilities of patient \(x\) (with condition \(X\)) and patient \(y\) (with condition \(Y\)).**

|            | Average Current Patients’ Score (ACPS) | Average Former Patients’ Score (AFPS) | BAP (ACPS/AFPS) | Test Patient’s Score (TPS) | Test Patient’s Score Adjusted by BAP (TPS/BAP) |
|------------|----------------------------------------|--------------------------------------|-----------------|----------------------------|-----------------------------------------------|
| \(x(X)\)  | 6                                      | 4                                    | 1.5             | 4                          | \(2.67\)                                       |
| \(y(Y)\)  | 3                                      | 3                                    | 1               | 3                          | 3                                             |

Each of the patients in Case 1, \(x\) and \(y\), suffers from a different medical condition (\(X\) and \(Y\), respectively). Utilities are measured on a scale from 1 to 10, where 1 is the lowest and 10 is the highest. The average score for current patients with condition

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¹⁶ I am grateful to an anonymous reviewer for raising this distinction.
X is 6 and the average score for former patients with condition X is 4. The BAP for condition X is 1.5.\textsuperscript{17} Current patient \(x\) reports a score of 4 for condition X. The final score of current patient \(x\) is 2.67 (after being adjusted by BAP). On the other hand, the average score for current patients with condition Y is 3 and the average score for former patients with condition Y is 3. The BAP for condition Y is 1. Current patient \(y\) reports a score of 3 for condition Y. The final score of current patient \(y\) is 3 (after being adjusted by BAP).

A comparison of \(x\)'s and \(y\)'s scores after being adjusted by BAP suggests that we should give medical priority to patient \(x\) over patient \(y\) because the adjusted score for \(x\), 2.67, is lower than the adjusted score for \(y\), 3. But this means giving medical priority to a patient with a condition that is ranked with higher utility by every group whose judgements are taken into consideration (namely former patients, current patients, and the individual patient under evaluation). This ranking seems wrong.

As a first intuitive approach, we may want to stipulate that, when ranking two or more patients or medical conditions on the basis of their medical priority, a suitable measure for determining the medical priority of these patients should not give medical priority to the patient or to the condition that is ranked with higher utility by each of the evaluators whose judgements are taken into consideration by the measure. In other words, if all the evaluators give a higher score to a certain condition (\(X\)) than to another condition (\(Y\)), the overall score for \(X\) should be higher than the overall score for \(Y\).\textsuperscript{18} This can be stipulated as an adequacy condition for Eyal’s measure since the condition fits a certain intuition on how a measure of this sort should behave. The formulation of a set of adequacy conditions is usually the first step for deriving (a family of) formulas that operate in a given domain.

I take the above to be a weak dominance condition. This condition is akin to monotonicity, but weaker. Take three vectors (1, 2, 3) for each condition (\(X, Y\)), each of which represents the evaluators whose judgements Eyal aims at incorporating into his measure.

\[
X: (x_1, x_2, x_3) \\
Y: (y_1, y_2, y_3)
\]

\textsuperscript{17} Although Eyal claims that the average BAP in the studies on patients’ self-reported utility reviewed was 1.45 (and a tight range between 1.31 and 1.67 was observed) he also recognizes that the analysis of a larger set of conditions could show the existence of a less consistent value of BAP, and perhaps would only be similar across certain definable subtypes of health states, populations, and circumstances (\textit{Supra} note 1, at 272–273). Notwithstanding, Case 1 above is meant to serve only as an illustration of the general mechanics behind the functioning of BAP.

\textsuperscript{18} For the sake of the argument I assume here, with Eyal, that average scores are the right indicators of current and former patients’ scores, which grants the strong formulation of the monotonicity condition described in the next paragraph of the text. Depending on the distribution of the data for current and former patients, a weaker formulation of this condition could be more appropriate, eg ‘should be at least equal’ instead of ‘should be higher’. I elaborate further on the rationale for the use of average scores in section 4. Another reason to stick to the weaker formulation of monotonicity would be if one is interested in knowing what one ought to do, as opposed to being interested in strict betterness orderings. If one is interested in what one ought to do, one may be indifferent between \(X\) and \(Y\) above even if \(X\) is better than \(Z\) if, for example, \(X\) is only slightly better than \(Z\).
By monotonicity, if the value of each of the vectors in $Y$ is at least as great as the value of each of the vectors in $X$, and the value of one the vectors in $Y$ is strictly higher, then the overall value of $Y$ should also be higher than the overall value of $X$. Monotonicity might be too strong a condition for the purpose Eyal is interested in. Eyal wishes to give some extra weight to the judgements of the former patients as compared to the judgements of the current patients since the hypothesis that motivates his project is that former patients are not biased (or at least not as biased as current patients) and have higher epistemic access than current patients. Given this, if the vectors with strict higher value are the ones corresponding to the current patients’ scores (either the average of current patients or the test patient) this would not necessarily imply that the resulting value should be higher for that condition. Given Eyal’s original assumptions, he may want his measure to be insensitive to this difference (unless the difference is significant).

There can be different reasons for why BAP violates the weak dominance condition introduced above. One reason could be that BAP is biased in favor of former patients’ judgements. This goes further than the mere ascription of greater weight to their judgements over the judgement of current patients. BAP behaves in a way such that when there is a significant divergence between ACPS and AFPS (like in the case of condition $X$ in Case 1, where the scores are 6 and 4 for current and former patients, respectively), the average of former patients becomes overly dominant over the average of current patients. So even if we concede that greater weight should be assigned to the judgement of former patients, it is far from evident that a low average score from former patients should have such dominance over a high average score from current patients.

There might be other adequacy conditions or desirability criteria that a more balanced BAP measure should satisfy. At present, the measure gives the highest BAP (ie significant medical priority) to conditions for which current patients report significantly high utility (even the highest possible) and former patients report significantly low utility (eg when ACP = 10 and AFP = 1, BAP results in 10/1 = 10, a high score that drags down the test patient score significantly). Instead, intuitively the measure should give the highest BAP (ie significant medical priority) to conditions for which both former and current patients give significantly low utility (eg when ACP = 1 and AFP = 1), but BAP does not meet this condition (if ACP = 1 and AFP = 1, BAP results in 1/1 = 1, a score that does not drag down the test patient score).

Another potential explanation for the odd result in Case 1 could be that $x$ is an outlier patient of her condition given that her reported score diverges significantly from the score of current patients.\(^\text{19}\) Although this could be one of the reasons for the above result, it cannot fully explain it. Case 2 below is another simplified case where BAP is applied to the reported scores of two patients with two different medical conditions, disabilities, or treatments. Case 2 shows that even when the scores of the patients under evaluation match the average scores of current patients, BAP leads to unintuitive results. Here, despite the difference between the average scores of current patients for conditions $Z$ and $Z'$, between the BAP of those conditions, and between the scores of the two patients under evaluation ($z$ and $z'$), the adjusted scores of the two patients

\(^{19}\) I am thankful to an anonymous reviewer for suggesting this possibility.
turn out to be the same. This suggests that deviation from the average score of current patients cannot fully explain the unintuitive result in Case 1. In section 4, I elaborate further on the issue of the distribution of the data behind BAP and the role of outliers.

Case 2. Comparison between the utilities of patient $z$ (with condition $Z$) and patient $z'$ (with condition $Z'$)

| Average Current Patients' Score (ACPS) | Average Former Patients' Score (AFPS) | BAP (ACPS/AFPS) | Test Patient's Score (TPS) | Test Patient's Score Adjusted by BAP (TPS/BAP) |
|----------------------------------------|--------------------------------------|-----------------|-----------------|---------------------------------------------|
| $z(Z)$ 4                              | 2                                    | 2               | 4               | 2                                           |
| $z'(Z')$ 3                            | 2                                    | 1.5             | 3               | 2                                           |

Finally, there are other structural features of BAP that are worth mentioning as further explanation for the source and implications of the results discussed above. Take BAP applied to a given test patient score again and focus on the role of ACPS. The following equivalent transformation is helpful for this purpose.

$$
TPS_{\text{adjusted by BAP}} = \frac{TPS_{\text{ACPS}}}{ACPS_{\text{AFPS}}} = TPS \times AFPS \times \frac{1}{ACPS}
$$

Whenever ACPS = 1, ACPS does not have any effect on the final, adjusted score. If ACPS = 1, the fraction $1/ACPS$ equals 1 and so multiplying by this fraction is going to leave the rest of the factors in the equivalence unaffected. This result means that in those cases where the average of current patients equals 1, irrespective of what the scores of former patients and test patients are, the judgement of current patients will be fully disregarded. This goes further than the original aim of giving greater weight to the judgement of former patients due to their greater epistemic access. And although this might be an unintended result of Eyal’s formula, the complete disregard of current patient’s scores (even if only in a small range of cases) seems unjustifiable due to it being overly paternalistic.

A similar effect occurs if 1 is the value that AFPS takes. Whenever AFPS = 1, AFPS does not have any effect on the final, adjusted score. This is at odds with the aim of BAP, where the judgement of former patients is meant to be weightier than the judgement of current patients.

Going back to ACPS, BAP behaves in a way such that the higher the value of ACPS, the lower the overall value of the final, adjusted score. ACPS is in the denominator of the fraction and so the higher its value, the more it will drag down the value of the final score. And the lower current patients grade their condition, the higher the final, adjusted score for that condition will be. Below is an example of this inverted value contribution of ACPS to BAP. X, Y, and Z are three different conditions with the same given patient score (2), same AFPS (4), and different ACPS (8 for condition X, 6 for condition Y, and 2 for condition Z):
Case 3. Inverted value contribution of ACPS to BAP

|                  | Average Current Patients’ Score (ACPS) | Average Former Patients’ Score (AFPS) | BAP (ACPS/AFPS) Score | Test Patient’s Score Adjusted by BAP (TPS/BAP) |
|------------------|----------------------------------------|---------------------------------------|-----------------------|-----------------------------------------------|
| x(X)             | 8                                      | 4                                     | 2                     | 2                                             |
| y(Y)             | 6                                      | 4                                     | 1.5                   | 2                                             |
| z(Z)             | 2                                      | 4                                     | 0.5                   | 2                                             |

When AFPS and TPS are equal for all three conditions—X, Y, and Z—and the only factor that differs across these three conditions is ACPS, TPS adjusted by BAP recommends giving medical priority to condition X, which is the condition ranked comparatively the highest by current patients with that condition. This result is even more counterintuitive than the previous one in terms of the role given to ACPS in BAP. In this case, it is not that the judgement of current patients toward the final, adjusted score is disregarded (as for the range of cases where ACPS = 1), but rather that the formula gives ACPS an inverted role or value contribution; when all other factors are held equal, the higher current patients rank their condition, the more medical priority is recommended to give to them.

Additionally, final scores adjusted by BAP approach infinity the closer ACPS gets to 0. This means that the influence of ACPS becomes extremely large when ACPS is close to 0, ie the worse current patients consider their condition to be.20

IV. SAMPLING

Lastly, one may wonder about the sampling behind the mean scores of former and current patients used in BAP. Eyal does not specify the rationale for the use of mean scores in BAP for adapted patients and current patients.21 But both the size of the samples used to derive mean scores of different conditions, as well as the distribution and variability of the data are important aspects to understand whether mean scores are pertinent values to be used as a reference point for the kind of measure that Eyal proposes.

First, a small sample can invalidate the use of mean scores in some of these cases. It is important to determine thus how big the sample should be to guarantee some sort of normality in the data. And it might be that some conditions require greater samples depending on the tendency of patients with such conditions to give dissimilar scores.

Second, and most important, depending on how the distribution of the data looks (the distribution of the scores reported by current and former patients), mean scores might not be meaningful ‘adjusters’ of patients scores. Unless the distribution of the data resembles a normal, bell curve-kind of distribution, the mean might not be a good depiction of the data corresponding to reported scores of current and cured patients. And given the variability between the reported scores of different patients

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20 Note that ACPS cannot take some typical ranges of values (eg 0–10) since, given that ACPS is in the denominator, 0 is excluded from the valid values that ACPS can take.

21 Supra note 1, at 270–271.
for some conditions (something Eyal is aware of and that is behind the motivation of his own formula), it is plausible that the distribution of the reported scores of these two groups might resemble some kind of equal distribution containing a significant number of outliers (and thus not a bimodal distribution with sufficiently differentiated or polarized masses of scores). If that is the case, at least for some conditions, the median could be taken to be a more precise reference point than the mean score of current and former patients.

Finally, it is also plausible that the data for different conditions will have different distribution patterns depending on the subjective variability across different patients when it comes to experiencing that condition. If this is the case, different data models should be used for different conditions and different representations of the data should be used in BAP (ie use of mean or median). This would require a further examination of the data for different conditions and the variability in people's subjective responses to them, as well as hypotheses about why such variability occurs.

I take all these to be relevant factors for determining how to best build up a measure like BAP that avoids the results described above.

V. CONCLUSION
I’ve argued that appealing to the judgment of former patients can help in determining which patients should be given medical priority. This move does not necessarily commit Eyal to the judgment that patients under treatment are irrational. In this paper, I have focused on the structural aspect of Eyal’s proposed measure to adjust current patients’ scores, BAP. I have argued that BAP leads to some counterintuitive results that violate a basic adequacy condition for a measure like BAP. In other cases, the measure gives inverted weight to the scores that average and current patients would be expected to have. It is important to stress that this behavior does not speak against the motivation for Eyal’s BAP. If my interpretation of Eyal’s proposal is correct, though, it puts pressure to come up with an amendment or a more balanced measure. A fruitful departure point, I have suggested, could be to develop a thorough analysis of the distribution of scores of former and current patients for different conditions to try to establish relevant patterns and determine hypotheses that may explain the differences in scores between them.

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