



2023

## The case for patient-reported pleasure

Preston Long  
*Medical University of Vienna*

Tanja Stamm  
*Medical University of Vienna*

Follow this and additional works at: <https://pxjournal.org/journal>



Part of the [Health Psychology Commons](#), and the [Medical Humanities Commons](#)

### Recommended Citation

Long P, Stamm T. The case for patient-reported pleasure. *Patient Experience Journal*. 2023; 10(3):13-14.  
doi: 10.35680/2372-0247.1853.

This Commentary is brought to you for free and open access by Patient Experience Journal. It has been accepted for inclusion in Patient Experience Journal by an authorized editor of Patient Experience Journal.

## The case for patient-reported pleasure

Preston Long, PhD, MSc, MA, *The Medical University of Vienna*, [preston.long@medunivien.ac.at](mailto:preston.long@medunivien.ac.at)

Tanja Stamm, PhD, MSc, MBA, *The Medical University of Vienna*, [tanja.stamm@medunivien.ac.at](mailto:tanja.stamm@medunivien.ac.at)

### Abstract

Pleasure is a cornerstone of human behavior. Its lack of consideration in the medical sciences has been to the detriment of all patients. The process of including pleasure as a medical outcome has multiple beginnings. A health-related pleasure scale must be developed for clinical purposes and original research must be conducted to establish the added value of measuring pleasure. Treatment comparisons, prediction models for recovery, side-effect investigations, and more may benefit from the collection of patient-reported pleasure. Furthermore, simply inquiring about a patient's pleasure may serve as a positive intervention by giving them permission to discuss more than the illness in their life. This can enhance the patient-provider relationship and expand the goal of treatment from illness elimination to wellness expansion. Reporting on pleasure can also benefit patients by reallocating their attention towards the positive, rather than the often consistent orientation towards the negative as seen in most patient questionnaires. When we consider what treatments to discuss, we need to know the areas of life from which our patients draw pleasure. The experience of pleasure is what keeps us alive and in pursuit of life. The seeming discomfort and resulting avoidance of medical professionals around the topic of pleasure may be one of the most significant remaining examples of societal stigmas impacting healthcare today.

### Keywords

PREMs, PROs, wellbeing, QoL, measurement, pleasure, wellness

Healthcare providers increasingly recognize the importance of collecting patient-reported outcomes (PROs) in hospitals. Typical PROs include measures such as sexual functioning, quality of life, and fatigue. These have been shown to provide valuable clinical insight.<sup>1</sup> However, one outcome that has been significantly overlooked is pleasure. Pleasure is a fundamental aspect of quality of life and should not be disregarded in the medical sciences. Incorporating pleasure as a medical outcome could yield multiple benefits. There has been such a paucity of health-related pleasure research though that there is no means whatsoever to measure pleasure as an outcome.

Hence, there is a need to develop a pleasure scale specifically designed for clinical purposes. There are scarcely any health-related pleasure scales available. The Snaith-Hamilton Pleasure Scale (SHAPS) is one of the few widely validated measures available, but it was not intended for clinical decision-making.<sup>2</sup> The only other relevant measures, such as the self-assessment anhedonia scale (SAAS), were developed for and normalized on patients with severe mental illnesses such as schizophrenia.<sup>3</sup> And importantly, these scales all focus on the absence of pleasure, or anhedonia. A pleasure scale tailored for use in a typical clinical setting, designed as a patient-reported outcome, does not currently exist. An important distinction of scales use in this context is to assess changes in a patient's capacity for pleasure across

multiple domains, rather than to understand the sources of their pleasure, such as from a psychology of personality perspective. An operational definition of pleasure is also required. Pleasure, as used here (and suggested for use in a PRO measure) is defined as: any positive sensory experience which exists in a particular moment (a bite of food), or in a sustained series of moments (intercourse). The source of pleasure will always be externally observable through our senses. The feelings associated with pleasure are desire, motivation, and enjoyment. The behaviors associated with pleasure are approach and seeking. Domains often associated with pleasure include hobbies, sensory experiences, food/drink intake, desire/motivation, and social interaction.

Following the development of the measure, research must be conducted to assess the value of measuring pleasure. Changes to a patient's reported level of pleasure resulting from food intake could, for example, inform on treatment comparisons, recovery prediction, or side-effect investigations. An initial pleasure scale would offer immediate value to assess individual patient changes from their baseline, and if enough pleasure data was standardly collected, it could predict changes to pleasure levels by disease group or treatment type.

While domains like human factors psychology/engineering routinely investigate pleasure, its value has been largely ignored in healthcare. However, incorporating pleasure

into our understanding of human health would undoubtedly prove useful. For example, let us imagine that a clinical trial was conducted comparing treatment A and treatment B. Both treatments demonstrated an equal reduction in disease severity and associated symptomology. However, treatment B maintained a higher level of daily pleasure in the subdomains of social interaction and exercise and thus is the better treatment choice. At present, this information is completely missing from our patients' profiles.

There could be an additional implicit benefit from measuring pleasure through the mere-measurement effect as well. The mere-measurement effect is the psychological phenomenon in which exposure to a question has an impact on the responder's perceptions of behaviors. This occurs primarily through priming and attentional redirection.<sup>4</sup> For instance, asking patients about their intent to undergo a procedure can increase the likelihood of its selection. Thus, we must consider the effects we have on patients through regular assessments, as well as how we might harness this effect to provide a positive intervention during measurement with constructs like pleasure. If frequent pain assessments can increase a patient's pain, would the same work with pleasure? Inquiring about pleasure may redirect the patient's attention towards the positive rather than the negative, which is the most common orientation in patient questionnaires.

Furthermore, inquiring about a patient's pleasure can serve as a positive intervention and produce clinical value by allowing patients to discuss the positive aspects of their lives. Pleasure's inclusion in the provider-patient dialogue will provide caregivers with a more holistic understanding of their patients, while also empowering patients to present a more complete picture of themselves to their caregivers. Would we want to recommend an intervention with mild benefits if we knew it risked the elimination of a patient's primary pleasure source? As this claim sounds reasonable to most, one must wonder why such a significant construct has been so neglected.

There is a deeply rooted stigma - explaining why this fruit remains on the tree - against the scientific exploration of pleasure, to which the essence can be captured as, "Pleasure is tertiary to our wellbeing." This argument seems reminiscent of a researcher proposing *Quality of Life* as an important construct in the 1800s and being met with the flippant response "Quality of Life!? Being alive is quality enough." Today of course, quality of life is a well-established outcome measure used in a wide range of human sciences.<sup>5</sup>

The problem-oriented approach prevalent in medicine may have also contributed to the neglect of pleasure. We seek to remove illness rather than bolster health. This explains why it is far more common to discuss or measure anhedonia, the absence of pleasure. The focus is often on the removal of pain without consideration of pleasure. However, pleasure is as vital as pain. Together, they are the two anchors of the human experience; we approach pleasure and avoid pain. Thus, the exclusion of pleasure from the medical sciences is currently a significant oversight. And though the present reader may agree, have you ever seen *pleasure* as a keyword in a scholarly article in medicine? It is unlikely. Pleasure must be viewed as a need rather than a luxury or an afterthought.

In conclusion, adopting pleasure as a patient-reported outcome can generate valuable insights into a patient's health and well-being. It is crucial to first develop a pleasure scale specifically for clinical use in the general hospital setting. It will then be necessary to conduct research exploring the ability of health-related pleasure to inform on treatment comparisons, recovery prediction models, and more. Lastly, the inherent positive effects of measuring pleasure should be assessed. By considering pleasure alongside other PROs, healthcare providers can improve patient care and promote a more positive and holistic approach to patient well-being.

## References

1. Retzer, A., Aiyegbusi, O. L., Rowe, A., Newsome, P. N., Douglas-Pugh, J., Khan, S., ... & Calvert, M. (2022). The value of patient-reported outcomes in early-phase clinical trials. *Nature medicine*, 28(1), 18-20.
2. Franken IHA, Rassin E, Muris P. The assessment of anhedonia in clinical and non-clinical populations: Further validation of the Snaith-Hamilton Pleasure Scale (SHAPS). *Journal of Affective Disorders*. 2007;99(1-3):83-89. doi:10.1016/j.jad.2006.08.020
3. Olivares, J. M., Berrios, G. E., & Bousoño, M. (2005). The Self-Assessment Anhedonia Scale (SAAS). *Neurology, Psychiatry, and Brain Research*.
4. Morwitz VG, Fitzsimons GJ. The Mere-Measurement Effect: Why Does Measuring Intentions Change Actual Behavior? *Journal of Consumer Psychology*. 2004;14(1-2):64-74. doi:10.1207/s15327663jcp1401&2\_8
5. Burckhardt CS, Anderson KL. The Quality of Life Scale (QOLS): Reliability, Validity, and Utilization. *Health and Quality of Life Outcomes*. 2003;1(1):60. doi:10.1186/1477-7525-1-60