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Perspective

Epistemic Injustice in Patient-Reported Outcome Measures

Katarzyna Ramirez^{1*}, Katrin Gallagher² and Sanne Peeters³¹Department of Public Health Ethics, Shannon University Centre for Bioethics, Ireland²Department of Bioethics, Shannon University Centre for Bioethics, Ireland³Department of Bioethics, Meuse Institute of Bioethics and Law, Belgium

ABSTRACT

Patient-reported outcome measures (PROMs) were designed to give patients' own accounts of their symptoms and function a legitimate place in clinical evidence, correcting a long-standing overreliance on clinician-observed data.

This perspective argues that the instruments built to serve this corrective function can themselves reproduce epistemic injustice, understood as harm done to a person specifically in their capacity as a knower.

We distinguish testimonial injustice, in which a patient's scored self-report is discounted downstream based on their social identity, from hermeneutical injustice, in which fixed item sets and a validated vocabulary leave some experiences uncodeable in the first place.

Drawing on recent work on contested illness, chronic pain, gendered symptom interpretation, and rare adverse-event reporting, we show how these two forms of injustice operate at different points in the measurement pipeline, from instrument design through score interpretation.

We conclude that participatory item development, periodic revalidation against patient testimony, and mixed-methods designs pairing structured scores with narrative supplementation offer the most promising route toward PROMs that are fair to the patients they are meant to represent.

Keywords: epistemic injustice; patient-reported outcomes; testimonial injustice; hermeneutical injustice; clinical measurement

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Corresponding Author: Katarzyna Ramirez

E-mail Address: k.ramirez@sucb.ie

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INTRODUCTION

Patient-reported outcome measures were introduced, in large part, as a corrective. For decades clinical research and clinical practice had relied almost entirely on what could be observed, measured, or inferred by a

clinician -- blood pressure, tumor volume, laboratory values -- while the patient's own account of how they felt was treated as too subjective to count as real data. PROMs promised to change that by giving patients a standardized, validated instrument through which their

symptoms, function, and quality of life could enter the medical record as legitimate evidence [1]. That promise has been taken seriously: PROMs are now embedded in oncology trials, national quality-of-care metrics, and routine outpatient workflows across much of the world [2].

What has received less attention, until recently, is a more uncomfortable possibility: that the instrument built to let patients speak for themselves can itself reproduce the very asymmetries it was meant to correct. A PROM is not a neutral conduit for a patient's testimony. It specifies in advance which experiences are askable, in what language, on what scale, and with what response options -- and those specifications are set by researchers and clinicians, not by the patients whose experiences are being captured [3]. When a patient's suffering does not map cleanly onto the items a questionnaire offers, or when their answers are quietly discounted because their symptoms lack an accepted biomedical explanation, something has gone wrong that mere measurement error cannot describe. Miranda Fricker's concept of epistemic injustice -- harm done to a person specifically in their capacity as a knower -- gives that wrong a name [4]. This review asks what epistemic injustice looks like when it operates through, rather than despite, a supposedly patient-centered measurement tool.

EPISTEMIC INJUSTICE AS A FRAMEWORK FOR CLINICAL ENCOUNTERS

Fricker distinguishes two forms of epistemic injustice. Testimonial injustice occurs when a hearer gives a speaker's word less credibility than it deserves because of a prejudice attached to the speaker's social identity -- a woman's pain dismissed as anxiety, an older patient's cognitive complaint attributed reflexively to age. Hermeneutical injustice is subtler: it occurs when a person's experience cannot be properly understood, by themselves or by others, because the shared conceptual resources needed to interpret it are missing or underdeveloped, often because the group most affected has been excluded from the practices that generate those concepts [4]. Carel and Kidd's foundational application of this framework to healthcare argued that patients are especially vulnerable to both forms of injustice simply by virtue of being ill: illness already diminishes a person's authority in ways that make their testimony easier to discount, and the language of biomedicine is generally not built from the patient's own conceptual starting point [5].

Subsequent work has traced these dynamics into specific clinical populations. Patients with contested or medically unexplained conditions such as chronic fatigue syndrome have been shown to experience a particularly acute form of testimonial injustice, in which the absence of a confirmed biomarker becomes, in practice, a reason to doubt the patient's report rather than a reason to investigate further [6]. Work centering patients' own accounts of chronic pain care has argued

that a genuinely person-centred model of care needs to treat this recognition problem as a design requirement, not an afterthought to be addressed once a standardized instrument is already in place [7]. Kidd and Carel extended the analysis to illness more broadly, arguing that hermeneutical marginalization compounds over an illness trajectory as patients are repeatedly asked to translate their experience into terms clinicians already recognize [8]. Qualitative work on chronic pain has documented the same pattern in patients' own words: pain narratives that do not fit the expected clinical script are treated as exaggerated or psychogenic, producing an experience many describe as feeling as though their credibility as a person, not just as a patient, has been undermined [9,10]. A recent narrative review of rheumatoid arthritis care documented how ageism compounds testimonial injustice specifically, with older patients' reports of disease flare more likely to be attributed to normal aging and treatment intensification correspondingly delayed [11]. Table 1 organizes the mechanisms this literature has identified by where in the clinical encounter they typically operate, and Figure 1 gives a schematic comparison of how far standard PROM practice and participatory PROM design go toward addressing each.

Table 1. Mechanisms of epistemic injustice identified in the PROM literature, organized by where in the measurement process they operate.

Locus	Mechanism	Type of injustice	Illustrative population
Instrument design	Fixed item sets exclude experiences absent from the original validation sample	Hermeneutical	Rare disease, contested/unexplained illness
Instrument design	Structured formats treat unstructured patient reports as evidentially inferior	Participatory epistemic injustice	Rare adverse-event reporting
Score interpretation	Clinicians discount discordant self-reports based on the patient's identity	Testimonial	Women, older adults
Score interpretation	Symptom scores reattributed to psychological cause absent a confirmed biomarker	Testimonial	Chronic fatigue syndrome, chronic pain
Conceptual vocabulary	No available concept exists for an atypical symptom presentation	Hermeneutical	Mental health, novel symptom clusters

THE INSTRUMENT AS GATEKEEPER: WHAT COUNTS AS A CODABLE SYMPTOM

A PROM does not ask patients to describe their experience in their own words; it asks them to select from a menu built during instrument development, usually by clinicians and psychometricians working from existing biomedical categories. That design choice has genuine methodological justification -- standardized items are what make a PROM scoreable, comparable across patients, and usable in a trial -- but it also means that whatever a patient experiences that does not correspond to an existing item simply does not enter the record. Recent work on communication in clinical encounters has described this as a structural form of epistemic injustice distinct from any individual clinician's bias: the tool itself pre-filters what testimony is even eligible to be heard, before a human hearer's prejudice ever comes into play [12]. A more general account of health communication has argued that framing patients' difficulty in being understood purely as a "health literacy" deficit on the patient's side obscures how much of the interpretive burden is actually built into clinical tools and vocabulary that patients had no part in designing [13].

This gatekeeping function is not evenly distributed across patient populations. Patients whose conditions were not well represented in the original item-development samples -- a familiar problem for rare diseases, for conditions disproportionately affecting marginalized groups, or for symptoms with strong cultural variation in how they are described -- are more likely to find that a validated PROM simply has no good item for what is happening to them. Analyses of drug safety monitoring have shown a related, more severe version of this problem: rare adverse events reported by patients through relatively unstructured channels were repeatedly treated as anecdotal and epistemically inferior to structured trial data, a pattern the authors describe as participatory epistemic injustice, in which a class of evidence is discounted not for any flaw in its content but because of how and by whom it was generated [14]. The same logic applies, in miniature, every time a PROM's fixed-response format forces an experience into the nearest available category rather than the correct one.

TESTIMONIAL INJUSTICE AND THE SOCIAL IDENTITY OF THE RESPONDENT

Even once testimony has been captured on a validated instrument, its downstream interpretation is not immune to identity-based discounting. A study of thyroid care found that patient-reported symptom burden was interpreted differently by clinicians depending on the reporting patient's gender and on the specialty of the treating physician, with women's reports of persistent symptoms more likely to be attributed to psychological rather than physiological causes even when scored on the same standardized scale [15]. This is testimonial injustice operating

downstream of the PROM itself: the instrument successfully captured the patient's report, but clinical uptake of that report was still filtered through identity-based credibility discounting. Qualitative interviews with chronic pain patients describe the resulting experience starkly, with participants reporting that having their pain doubted despite a documented score felt like having their basic standing as a reliable witness to their own body called into question, sometimes described using the language of medical gaslighting [10]. A related interview study found that patients frequently framed the problem in explicitly relational terms, noting that clinicians are, in one participant's words, not "almighty god" but fallible people whose judgment can override a documented self-report for reasons that have nothing to do with the report's accuracy [16].

A further complication is that PROM scores are frequently interpreted by clinicians alongside other information -- observed affect, chart history, presentation style -- in ways that can override or discount a discordant self-report. Clinical culture has generally treated this as clinical judgment rather than potential bias, but from an epistemic-injustice perspective it raises the question of what a validated, quantified score is actually for if a clinician remains free to discount it whenever it conflicts with their own prior impression of the patient. This tension has no easy resolution, since some degree of clinical interpretation is unavoidable and often appropriate, but it does mean that PROM adoption alone cannot guarantee that a patient's testimony is credited proportionately to its evidential weight.

HERMENEUTICAL INJUSTICE AND THE LIMITS OF A FIXED VOCABULARY

Hermeneutical injustice raises a harder problem, because it is not primarily about clinicians discounting patients but about a shared vocabulary that has not yet caught up with certain patients' experience. Mental health populations have been a particularly well-studied site for this: patients experiencing novel or atypical symptom presentations often lack an available diagnostic concept that fits their experience, forcing a choice between mischaracterizing their own state in available clinical terms or remaining, in effect, unintelligible to the system meant to help them [17]. Standard PROMs compound this problem in a specific way -- because their items are fixed at the point of validation, they cannot easily incorporate new conceptual resources as they emerge from patient communities, even when qualitative research has already identified a gap. A PROM validated a decade ago will still be administered today using a vocabulary that patient communities may have already moved past.

This is one reason contested-illness populations, in particular, feature so heavily in the recent epistemic injustice literature on measurement instruments.

Where a diagnostic and conceptual apparatus is itself unsettled, as with chronic fatigue syndrome or chronic pain conditions without a clear structural correlate, any PROM built from that apparatus inherits its gaps, and patients are left trying to communicate through an instrument that was never given the vocabulary to hear them accurately [6,9]. Philosophical work distinguishing genuine hermeneutical injustice from adjacent phenomena -- ordinary communication failure, or a patient's own difficulty articulating a genuinely inchoate experience -- has cautioned against treating every instance of a patient going unheard as evidence of injustice specifically, since collapsing the distinction risks diluting the concept's explanatory force [9]. That caution is well taken, but it does not remove the underlying problem: fixed-vocabulary instruments are structurally poorly suited to tracking a population's evolving self-understanding of a genuinely contested condition.

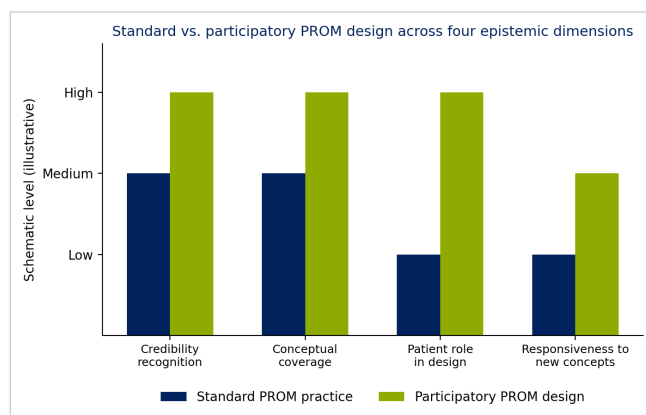
TOWARD EPISTEMICALLY FAIRER MEASUREMENT

The literature converges on participatory design as the most consistently proposed remedy, though not necessarily a complete one. Involving patients directly in item generation and instrument revision -- rather than only in pilot testing of an instrument researchers have already finalized -- allows conceptual gaps to surface before, rather than after, an instrument becomes the fixed reference point for a disease area [13]. The methodological literature on PROM reporting has moved in a parallel direction: reporting standards for patient-reported outcomes in clinical trials increasingly require that trialists specify a rationale for instrument choice and disclose missing-data patterns that might otherwise mask whose experience the chosen instrument fails to capture [18].

Handbook-level treatments of epistemic injustice have emphasized that structural remedies -- changes to institutions, tools, and training, not merely to individual clinician attitudes -- are necessary because the injustice in question is frequently produced by systems rather than by any single biased actor [19]. Applied to PROMs specifically, this suggests that periodic, transparent revalidation against patient testimony, mixed-methods designs that pair a structured score with an open-ended narrative component, and explicit institutional accountability for how discordant self-reports are handled in clinical decision-making are more promising than simply training individual clinicians to trust patients more. None of these measures fully resolves the tension between standardization, which is what gives PROMs their evidential and comparative value, and epistemic responsiveness, which is what would make them fully fair to patients whose experience the instrument was not originally built to capture. Table 1 and Figure 1 summarize where standard practice currently sits on this trade-off and what a more participatory model

would need to change.

Figure 1. Schematic, illustrative comparison of standard versus participatory PROM design across four epistemic dimensions (Low/Medium/High axis; not derived from a single empirical study).



CONCLUSION

Patient-reported outcome measures were built to solve an epistemic injustice -- the historical exclusion of the patient's own account from what counts as clinical evidence -- and to a real extent they have done so. But the instrument's design choices, made necessarily in advance and by people other than the patients who will use it, create their own, subtler versions of the same problem: testimony that is captured but then discounted along identity lines, and experience that cannot be captured at all because the available vocabulary was never built to hold it. Recognizing PROMs as a site of possible epistemic injustice, rather than treating standardization as a guarantee against it, does not require abandoning quantified patient-reported measurement. It requires building revision, participatory item development, and narrative supplementation into how these instruments are made and used, so that the tool meant to let patients speak does not become one more filter deciding, in advance, what they are permitted to say.

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Conflict of Interest

The authors declare no conflicts of interest relevant to this work.

Author Contributions

Katarzyna Ramirez conceived the review, synthesized the literature on testimonial injustice and clinical credibility, and drafted the initial manuscript. Katrin Gallagher developed the sections on instrument

design and hermeneutical injustice and critically revised the manuscript. Sanne Peeters contributed the analysis of participatory remedies and reporting standards and provided final approval of the submitted version. All authors read and approved the final manuscript.

Ethics Statement

As a literature review synthesizing previously published, publicly available research and policy analysis, this article did not involve new data collection from human participants and did not require institutional ethics committee approval.

Data Availability

No new data were generated or analyzed for this review. All sources discussed are cited in the reference list and are publicly available through their respective publishers.

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