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Patient-reported Outcome Measures – A Call for More Narrative Evidence

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Abstract

This article puts forward the need to reconsider the current underlying quantitative approach underpinning the application of patient reported outcomes, to a mixed methods approach through the tandem use of patients' narrative that enables informants in addition to their scores to express the reality of the ways in which their lives are physically and mentally impacted by their health status.

Keywords

narrative analysis, qualitative methods, patient-reported outcomes, narrative enquiry

Introduction

In this commentary I argue that the application of patient-reported outcome measures (PROMs) results in a narrow conception of evidence by the overriding of the subjectivity of individual experiences, beliefs and judgements. On this basis I maintain that there are convincing reasons as to why there is the need to extend the range of quantitative evidence resulting from the application of PROMs to the inclusion of narrative evidence. In doing so, it marks a significant shift from the current perspective of working within a logical-positivist paradigm of purely quantitative data to the inclusion of an auto biographical narrative.

The notion that scientific enquiry can be conducted along clear and rational lines and that our beliefs and theories must be translatable into first-order predicate logic, has been for many generations an issue of controversy (1). My argument is that working within the logical-positivist paradigm – the pursuit for objectivity – forces us into a mode of scientific enquiry that impedes our ability to get the most insightful answers to our questions. In essence however – implicit in the use of PROMs – the 'absolute truth' is out there waiting to be collected, categorised and analysed once a good measuring instrument is available (2). However, Dewey (3) quotes "Any problem of scientific inquiry that does not grow out of actual (or 'practical') social conditions is factitious; it is arbitrarily set by the inquirer".

While my appeal here is for first-person experience or first-order account, it is acknowledged that this can be problematic for practitioners in the application of PROMs where the need is to obtain a standardized metric score that represents the researcher's pre-defined construct and where the RCT is the gold-standard for this requirement.

In what follows I will attempt to discuss the relevance of the use of narrative in the application of patient reported outcome measures in the understanding of the experience and behavior of living with an illness.

What is Narrative?

A narrative, story or tale is any account of a series of related events or experiences. As a linguistic form, narrative has a number of distinguishing features (4). First, it is both finite and longitudinal – events are arranged in a particular order with an ending. Secondly, narrative is concerned with the individual rather than a simple description of what they do or has been done with them, but how they feel. Thirdly,to quote Greenhalgh & Hurwitz (4):

> "The narrative also provides information that does not pertain simply or directly to the unfolding events. The same sequence of events told by another person to another audience might be presented differently without being any less 'true.' This is an important point. In contrast with a list of measurements or a description of the outcome of an experiment, there is no self-evident definition of what is relevant or what is irrelevant in a particular narrative".

Misak (1) defines narrative from two perspectives around the distinction put forward by Peter Goldie (5). These are the

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internal perspective – straight forward narrative – where we put ourselves in the shoes of the story teller and by listening and reflection we may gain insights into how an event was experienced. Alternatively, there is the external perspective, where the focus is on the interpretation and evaluation of the narrator of an event (1).

The Role of Narrative Within PROM Usage

Neal and Strang (6) consider that the PROM developer tends to gloss over human diversity and the day the day-to-day, moment by moment will deliver different fluctuations in how people perceive their health status. What I refer to in the context of PROM use, as the 'genealogy of health perception' our representations of illness, health and quality of life, being radically shaped by contingent facts such as family history, a moment in time, culture and experience.

However unlikely it is to develop a "perfect" PROM and measure "*objective truth*," as Misak (1) quotes:

> "…nothing will deliver to medicine what it is seeking" "Subjectivity, for want of a better word, cannot be drummed out of its [medical] enquiries."

Misak (1) argues that knowledge and inquiry are underpinned by the idea that we must take our beliefs and theories to be responsive to experience and evidence. This being the case should the question therefore be that there is a need to take a broader perspective of evidence than that imposed by the logical-positivist underpinning the use of PROMs would have it? My answer to this question will be that indeed other kinds of evidence – autobiographical narrative – are equally legitimate. Hesse-Biber (7) argues that taking a qualitative perspective, several research traditions will have as a fundamental principal that reality is socially constructed. However, I would go so far as to say that currently qualitative evidence as opposed to quantitative data is and will remain problematic for adherents of PROMs as the consequence of a preoccupation with an outdated gold standard of scientific enquiry. A stance required by current regulatory requirements (8).

It can be argued that narrative is rife with exaggeration, deception, omission and self-deception (1). Nonetheless, in contrast, respondents answering a fixed-format PROM question can provide what may seem as an acceptable answer for any number of reasons including the respondent:

- Provides an inaccurate answer which is believed to be correct
- Does not know the correct answer but, provides an answer regardless
- Fails to interpret the question as intended by the researcher and provides an answer based on her/his interpretation of the question
- Provides an answer which s/he thinks the researcher wants

Nevertheless, there is the need to be sensitive to the fact that narrative can be biased in one form or another, although Tversky (9) notes that listeners of narrative are aware of the possibilities for exaggeration and omission. Yet, if narratives are to play a critical role in our enquiry, we need to be confident in our judgement and evaluation of their content and that our reasons for acceptance are open to scrutiny. Value-judgement and subjectivity will clearly come into play and as a result stresses the rigor of our interpretation; therefore we need to look for internal coherence, consistency with other evidence and the power of explanation.

Greene et al. (10) and Schoonenboom & Johnson (11) produced a list supporting the rationale for the use of a mixed-methods research which includes the following:

- Context: The combination of both qualitative and quantitative is justified by providing a contextual understanding
- Confirm and discover: Using qualitative data to generate hypotheses and using quantitative research to test them within a single project
- Diversity: Learning from different perspectives, multiple participation, comparison of multiple perspectives

Wells (12) provides a framework for considering the trustworthiness – validity and relevance – of narrative research. What were the conditions under which the narrative was produced? Has the full text been subjected for analysis? Have the analytic categories used in the analysis been specified? Why do aspects of the text that do not support the major claims not undermine them? Has the broad context in which the text was produced been discussed?

As they stand, PROMs are a valuable tool – within the context of a positivist paradigm – by producing different scores, where improving scores are taken as evidence of efficacy of treatment or improved health status and or quality of life (6). The use of PROMs results in a shift in focus from the reflection on individual patients' to populations. The concept of evidence resulting from the application of a PROM is a metric score, representing a construct based not on first-hand accounts of patient experience but, an amalgam of second-order accounts of patients' experiences. As a result the patient's 'illness narrative' by offering their 'own story' is lost along the way (13,14). This lack of the narrative context of illness denies us the framework for the understanding a patient's problems holistically – the existential problems of inner hurt, despair, grief and moral pain that can accompany illness (4). But also the individual's social construction of the illness experience where culture and individual personality play a significant role (15). Narrative offers us a means of understanding from the patient's perspective the why, what and how of the illness. It provides an understanding that no other means can offer.

Narrative is the phenomenological form in which patients experience illness is given structure. However, the two opposing models of positivism – pure quantitative data – and

phenomenology – narrative – can be seen to be reconcilable at the level of understanding patients' experiences. The proposition being that the two contrasting views of reality being used in tandem can provide more personalised and insightful accounts of peoples' health experiences and behaviour. The challenge being, the need to capture the individual experiences and to obtain a numeric score on a scale of some predefined construct (positivism), while defending the approach to the understanding of human affairs (6).

Finally, integration of both the qualitative and quantitative data such as the merging of data sets, using a theoretical framework for binding together the data sets can for example be used to establish whether the qualitative and quantitative components provide convergent results (11).

The Type of Narrative and its Analysis

Although having argued the case for the need of narrative evidence to gain subjective insights into the patient's perspective on the self-reporting of outcomes, so far in this commentary I have discussed narrative in a broad sense. There are however, two questions. First, what kind of narrative would best represent the kind of evidence to inform patient-reported outcomes and secondly, how should narrative be analysed.

There are a number of methods for acquiring narrative data which include conversations, observation, autobiographies, transcripts of in-depth interviews, focus groups, diaries, letters etc. In the case of patient reported outcomes, while not being able to be specific, the focus is the story behind the respondent's responses to the PROM.As such in-depth interviews would seem to be uniquely appropriate to presenting a case-based method for narrative analysis where the analysis and interpretation of the transcriptions complement the PROM scores within a mixed methods paradigm. For the researcher this requires the construction of a synthesis through immersion in the data, listening to the interview recordings and rereading the transcripts (16).

Narrative analysis refers to a cluster of analytic methods for interpreting texts which can be categorized on the basis of whether they focus on the narrative content or structure, with the thematic version interrogating what a story is about, while the structural version asks how a story is composed to achieve particular communicative aims (17). One could also add the dialogic/performance narrative analysis, which focusses on the context and views narratives as being multivoiced and co-constructed (18).

In general narrative enquiry is focused on the study of the particular and is case-centred (18,19). However, a distinction needs to be made between narrative analysis which reveals the constructed story of an individual participant, and paradigmatic analysis which uses both inductive and deductive means to identify common and contrasting themes between narratives (20). For example, Grob et al. (21) applied a methodology in which a two-part coding schema was developed to categorize the narrative content of 348 patients in terms of key aspects of the enquiry. However, such approaches can eliminate the features that are the hallmarks of narrative, for example through the distillation of detailed accounts into coding units (18,19).

The task for the analytical method is to help inform and contextualize patients' PROM scores. The method chosen however, to achieve this will depend on the purpose of the enquiry. When the investigator's objective is to understand the narrative of individuals in relation to their quantitative score, narrative analysis enables the accumulation of detail to provide a fuller picture of the individual.

Each approach (individual narrative/category centred method) provides a different way of knowing the phenomenon with each providing unique insights.

Conclusion

To understand the efficacy of a clinical intervention requires the highest quality of information available, and where RCTs can be considered as the gold standard for this requirement. But, when it comes to the assessment of patients' health-status and health-related quality of life, I have argued that constrained by the straight jacket of logical positivism in the underpinning of its development and application, the PROM has reached its limit in the provision of information on patient experience and behaviour. While acknowledging that within this constraint PROMs can be a useful tool, I have argued that narratives of first-person experience – if subjected to a high level of critical scrutiny – can be of high quality and when used in tandem with PROM data can provide a deeper and more insightful account of patients' experiences.

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References

1. Misak CJ. Narrative evidence and evidence-based medicine. J Eval Clin Pract. 2010;16(2):392-7.
2. Buckingham A, Saunders P. The Survey Methods Workbook: From Design to Analysis. Wiley: Polity Press; 2004.
3. Dewey J. Logic: The Theory of Inquiry. New York: Henry Holt; 1938.
4. Greenhalgh T, Hurwitz B. Narrative based medicine: why study narrative? Br Med J. 1999;318(7175):48-50.
5. Goldie P. Narrative, emotion, and perspective. In: Kieran M, Lopes D (eds) Imagination, Philosophy, and the Arts. London: Routledge; 2003, pp.54-68.

6. Neale J, Strang J. Philosophical ruminations on measurement: methodological orientations of patient reported outcome measures (PROMS). J Ment Health. 2015;24-(3):123-5.
7. Hesse-Biber S. Qualitative approaches to mixed methods practice. Qual Inq. 2010;16(6):455-68.
8. U.S Department of Health and Human Services Food and Drug Administration (FDA) Guidance for Industry: Patient-Reported Outcome Measures: Use in Medical Product Development to Support Labelling Claims.
9. Tversky B. Narratives of space, time, and life. Mind Lang. 2004;19(4):380-91.
10. Greene JC, Caracelli VJ, Graham WF. Toward a conceptual framework for mixed-method evaluation designs. Educ Eval Policy Anal. 1989;11(3):255-74.
11. Schoonenboom J, Johnson RB. How to construct a mixed methods research design. Kolner Z Soz Sozpsychol. 2017;69(Suppl 2):107-31.
12. Wells K. Narrative inquiry. Qual Soc Work. 2011;10(4): 537-45.
13. Kleinman A. The Illness Narrative. New York: Basic Books; 1980.
14. Frank A. The Wounded Story-teller. Chicago, IL: University of Chicago Press; 1997.
15. Conrad P, Barker K. The social construction of illness: key insights and policy implications. J Health Soc Behav. 2010;51(Suppl):S67-79.
16. Frechette J, Bitzas V, Aubry M, Kilpatrick K, Lavoie-Tremblay M. Capturing lived experience: methodological considerations for interpretive phenomenological inquiry. Int J Qual Methods. 2020;19:1-12.
17. Figgou L, Pavlopoulos V. Social psychology: research methods. In: Wright JD (ed.) International Encyclopedia of the Social & Behavioral Sciences. 2nd ed. Oxford: Elsevier; 2015, pp.544-52.
18. Riesman CK. Narrative Analysis. Newbury Park, CA: Sage Publication; 1993.
19. Mishler EG. Models of narrative analysis: a typology. J Narrative and Life Hist. 1995;5(2):87-123.
20. Polkinghorne DE. Narrative configuration in qualitative analysis. Int J Qual Stud Educ. 1995;8(1):5-23.
21. Grob R, Schlesinger M, Barre LR, Bardach N, Lagu T, Shaller D, et al. What words convey: the potential for patient narratives to inform quality improvement. Millbank Quarterly. 2019;97 (1):176-227.