Developing a patient-reported outcome measure for patient experiences of social needs care

Abstract

Background: With the goal of advancing health equity, the US healthcare sector has expanded activities to identify and intervene in patients' experiences of social adversity, sometimes referred to as "social care". As social care is scaled, there is mounting pressure to assess the quality of these activities, compared to the quantity. Yet, no measure of patients' experiences with social care has been developed.

Objective: We conducted foundational qualitative research to understand key aspects of patients' experiences of social care to be incorporated into a patient-reported quality measure.

Methods: We recruited patients from across the U.S who 1) were aged 18 or older, 2) spoke either English or Spanish as their primary language, and 3) had an experience with social care in a clinical setting within the last 12 months. Using a semi-structured interview guide, we invited participants to describe their experiences and expectations related to social risk screening and social interventions, along with suggestions for improvement. We conducted a thematic qualitative analysis of interview transcripts using a mixed inductive-deductive coding approach.

Results: 30 people participated in interviews (16 English-speaking; 14 Spanish-speaking). Participants emphasized the importance of their relationship with their social care provider (SCP); their experiences of social care were influenced by their SCP's verbal and nonverbal demonstrations of empathy, linguistic and cultural alignment, and length of the patient-SCP relationship. Participants also valued the extent to which the screening, follow up, or resource attainment they received aligned with their priorities. Overall, these two aspects of social care were interconnected and patients placed varying levels of value upon each.

Conclusion: Our interviews suggest that the relational component is as important – if not more to some patients – than the functional aspects of social care. These factors can directly inform both the delivery of social care and future patient-reported social care experience measures.