METHODS, TOOLS, AND STRATEGIES

Development of Patient-Centered Disability Status Questions to Address Equity in Care

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Background: Patients with disabilities experience disparities in accessing and receiving high-quality health care services as compared to patients without disabilities. To address the disparities, health care organizations need to identify which of their patients have disabilities to track quality of care and provide appropriate health care accommodations. To date, no evidence-based sets of disability questions exist that serve these purposes. A study was conducted to identify patient-centered disability questions for health care organizations to determine which patients require health care accommodations and to track the quality of care experienced by patients with disabilities.

Methods: In the first of three phases, a focus group with patients and caregivers \( N = 54 \) and interviews with providers \( N = 15 \) were conducted to explore the disability questions that they believed were important. In the second phase, nationally recognized experts \( N = 17 \) participated in a modified Delphi panel to develop a set of disability questions. The third phase entailed cognitive interviews \( N = 46 \) with patients with and without disabilities to refine the wording of the disability questions identified through the previous rounds.

Results: Through the three phases, six essential questions and three additional recommended questions were identified. Questions addressed hearing, visual, motor, cognitive, communication, and learning disabilities, and the ability to conduct activities of daily living. An overall question for disabilities not included in the previous questions was also identified.

Conclusion: Through a rigorous, three-stage process that engaged multiple stakeholders, patient-centered disability questions were identified for health care organizations to use to identify disparities within their organizations and accommodations that address these disparities.

Health care organizations are required by the Americans with Disabilities Act of 1990 and the Rehabilitation Act of 1973 to provide equitable care to patients with disabilities.\(^1,2\) Despite this, a growing body of evidence demonstrates that patients with disabilities, as compared to patients without disabilities, experience disparities in the receipt of and access to high-quality, safe health care services.\(^3-10\) To address disparities in care, health care organizations first need to identify which of their patients have disabilities and know what those disabilities are so that they can make the appropriate accommodations.\(^11\)

Health care organizations often do not systematically document patients’ disabilities in patients’ medical records. Although some information regarding disabilities may be documented by providers in medical notes, this information is not easily accessible and often is inconsistently or inaccurately documented.\(^12,13\) Policies have called for health care organizations to systematically document patients’ disability status. First, a 2010 Joint Commission report, Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care: A Roadmap for Hospitals, stated that health care organizations should document patients’ mobility, communication, and literacy abilities for the purpose of informing patient-centered care.\(^14\) More recently, Section 4302 of the Patient Protection and Affordable Care Act (ACA) required that any federally supported “health care or public health program” collect data on race, ethnicity, sex, primary language, and disability status in order to document disparities.\(^15\) To date, there are no established sets of disability questions that serve the purposes of identifying disability-based health care disparities or patients who require health care accommodations.\(^11\)

To provide guidance for implementation of Section 4302 of ACA, in 2011 the US Department of Health and Human Services (HHS) recommended six disability status questions.\(^15\) These questions come directly from the American Community Survey (US Census) and identify people with hearing, visual, motor, cognitive, and activities of daily living (ADL) limitations. Although these questions provide vital information on the prevalence of disability in the population of the United States, they were not developed to, nor have they been used to, examine health care disparities at an organization level or identify patients who require health care accommodations. A survey of patients with and without disabilities showed that, while patients overwhelmingly supported the collection of disability status and had few privacy...
concerns with disclosing this information to their health care organizations, they believed that the HHS–recommended disability questions might not be comprehensive enough. Therefore, we conducted a study to identify patient-centered disability questions for health care organizations to use to determine which patients require health care accommodations and to track the quality of care experienced by patients with disabilities.

**METHODS**

We sought to identify disability questions using a three-phase process. In the first phase, we conducted focus groups and interviews with key stakeholders, including patients, caregivers, and providers. Our goal was to identify the questions each stakeholder group believed were important and garner feedback on the HHS–recommended disability questions. In the second phase, nationally recognized experts participated in a modified Delphi panel, in which we presented first-phase results, requested additional feedback, and developed a set of disability questions. In the third phase, we conducted cognitive interviews to refine the wording of the disability questions identified throughout the previous two rounds (see Table 1 and Figure 1).

The Institutional Review Boards at the Mayo Clinic (Rochester, Minnesota) and Brigham and Women’s Hospital (Boston) approved the study procedures.

**Phase 1. Focus Groups and Interviews with Patients, Caregivers, and Providers**

**Participants.** For the patient and caregiver focus groups, we recruited adult, English-speaking patients with disabilities and caregivers in southeastern Minnesota between June and October 2014. We actively recruited participants who represented a wide range of disabilities, including those with hearing, visual, motor, cognitive, and ADL disabilities. We did not limit the types of disabilities included. Targeted places for recruitment included patient support groups (for example, Parkinson’s disease support groups), state rehabilitation services (for example, state services for the blind), senior centers, the local Center for Independent Living, adult and pediatric rehabilitation clinics, and local disability advocacy organizations (for example, ARC and National Association for Mental Illness). We continued recruitment for additional groups until we successfully recruited patients from a range of disabilities and reached saturation in themes.

For the provider interviews, we recruited practicing physicians from a range of medical specialties through e-mail lists that targeted practicing physicians engaged in health services research at the Mayo Clinic between June and September 2014. We did not send follow-up e-mails after the initial recruitment e-mail, although some of the physicians who received the e-mail forwarded it to members of their

**Phase 2. Online Modified Delphi Panel with National Experts**

**Participants.** We engaged national experts in identifying the key disability status questions using the results from Phase 1.

**Results:**

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<th>Phase 2</th>
<th>Phase 3</th>
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<td><strong>Purpose</strong></td>
<td>Engage a panel of national experts in identifying the key disability status questions using the results from Phase 1.</td>
<td>Test and refine the questions identified by the expert panel in Phase 2.</td>
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<tr>
<td><strong>Participants</strong></td>
<td>National experts (N = 17)</td>
<td>Patients without disabilities (N = 20)</td>
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<td><strong>Methods</strong></td>
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