How do patients describe their disabilities? A coding system for categorizing patients' descriptions

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ABSTRACT

Background: To provide care that meets the values and preferences of patients with disabilities, health care providers need to understand patients' perceptions and understanding of their disability. No studies have explored patients' definitions of disability within the healthcare setting.
Objective: The aim of the study was to understand how patients' define their disability in the healthcare setting and to develop a coding system for categorizing how they describe their disability.
Methods: In 2000 all new outpatients at Mayo Clinic, Rochester, MN completed a form that inquired if they had a disability and if so, to write in the disability. The research team categorized the responses by disability type (e.g.: visual or physical) and how the patient described his disability or "disability narrative" (e.g.: diagnosis or activity).
Results: Within 128,636 patients, 14,908 reported a disability. For adults, lower limb (26%) and chronic conditions (24%) were the most frequent disability type and activity limitations (56%) were the most frequent disability narrative category. For pediatric patients, developmental disabilities (43%) were the most frequently reported disability type and diagnoses (83%) were the most frequent disability narrative category. Patients used different disability narrative categories to describe different disability types. For example, most adults reporting a mental health listed a diagnosis (97%), compared to only 13% of those with lower limb disabilities.
Conclusions: Patients had diverse descriptions of their disabilities. In order for providers and healthcare organizations to provide high-quality care, they should engage patients in developing a consistent, patient-centered language around disability.

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Introduction

Studies have demonstrated that patients with disabilities, as compared to patients without disabilities, report lower satisfaction with the quality of communication during their clinical encounters.[1,2] One potential contributor to this dissatisfaction could be a disconnect in how patients and providers perceive and define the patient's disability. For example, a patient who is Deaf might believe that his deafness is a part of his identity and connects him to the Deaf community, whereas a provider might have the perspective that deafness is something that should be medically treated. While multiple national surveys inquire about disabilities, these surveys primarily focus on functional activities in the community setting (for example, conducting errands alone),[3–5] potentially limiting their applicability to the healthcare setting. To engage in high-quality, patient-centered care, providers need to elicit patients' preferences, values and perceptions of their condition, which for patients with disabilities could include their perceptions of their disability. To date, no studies have explored how patients' define their disability within the healthcare setting.

In 2000, Mayo Clinic (Rochester, MN, USA) included on all forms for new patients a question inquiring if the patient had a disability. If the patient replied yes, then he/she was asked to write in the disability. The aim of this study was to categorize the open-ended

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responses from new patients in order to understand how they describe their disability when they are in the healthcare setting. Furthermore, through this process we aimed to develop a coding scheme for categorizing how patients describe their disability.

Methods

Study cohort

Between 1999 and 2001 all new outpatient encounters at Mayo Clinic included a disability status question in the required "Patient and Family History" form. The question asked "Are you disabled?" and if the patient selected "yes", he/she was asked to describe the disability in an open response field. All new patients during the time period received the form with the new questions. All open-ended responses were scanned into the electronic medical record and stored as an image file (pdf).

Mayo Clinic implemented the disability question in mid-1999 and discontinued it in mid-2001. We limited our analysis to the year 2000, the only year in which all new outpatients were asked the disability question. We included all pediatric and adult patients in our study sample. The study was approved by the Mayo Clinic Institutional Review Board.

Categorizing disabilities

For all patients who responded "yes" to the "Are you disabled?" question, a member of the research team transcribed all readable open-ended response images. Three members of the research team then conducted a content analysis on the transcribed responses.[6] The purpose was to create discrete categories to classify the disabilities. The research team embarked on an inductive, open coding system in which the codes were developed based on the patients' written responses. No pre-determined set of categories was used. The coding team included a PhD-trained Rehabilitation Sciences researcher (MM), a medical student (JR) and a doctoral student in linguistic anthropology (CH).

During the inductive coding process, two different coding schemes were developed. The first coding scheme was disability type. Examples of disability types included: cognitive disability, mental health disability, learning disability and communication disability (See Table 1 for a list of all disability types and examples of each.). The second coding scheme described *how* the patients described their disability, which we called "disability narrative". As we developed different codes, we observed that the scheme loosely resembled the World Health Organization's International Classification of Disability and Rehabilitation Research (ICF).[7] In this model, disability is described as the interaction of six factors, namely, (1) health condition, (2) body functions and structure, (3) activity, (4) participation, (5) environmental factors and (6) personal factors. The language patients used to describe their disabilities roughly aligned with these categories. For example, patients who were blind described their disability using the following terms: "blind" (health condition or disease), "bad eyes" (body functions and structure), "can't see" (activity), "can't go to work because of bad vision" (participation), or "legally blind" (environmental factors). One ICF category that we did not observe was "personal factors". We added an additional category of "symptoms", which included descriptions of "weakness" or "loss of strength". We defined any description of a governmental assignment of disability or disability benefits as an environmental factor.

The research team collaboratively developed the coding scheme, associated definitions, and coding rules including an algorithm to handle disability descriptions involving multiple existing codes. For example, a patient could say "weakness in hand" which included a symptom and a body part. In this example, weakness was viewed as the more prominent descriptor and so this was coded as "upper limb" for disability type category and "symptom" for the disability narrative category.

The team independently coded a set of disability responses and then met to define the coding categories and associated definitions. Coding schemes and associated definitions were finalized after six rounds. The team then independently coded the remainder of the disabilities; double coding 20% to establish reliability. Cohen's Kappa was 0.87 for the disability type and 0.79 for the disability narrative category, indicating good to excellent reliability.[8]

Results

Description of the sample

A total of 128,636 unique patients (112,997 adult and 15,639 pediatric) completed the patient and family history form in 2000. Of those patients, 108,059 (84%) reported no disability, including 94,381 (84%) adults and 13,678 (90%) pediatric patients. A total of 14,908 (12%) reported a disability, with 13,997 (12%) adults and 912 (6%) pediatric patients. Finally, 5668 (4%) did not respond to the general question, with 4619 (4%) of adults and 1049 (7%) of pediatric patients.

Of the 14,908 people who indicated that they had a disability, 2910 (20%) responses were unusable because the patient did not write in his/her disability, the disability description was not legible or the description of the disability was not informative (for example some patients wrote: "yes" or "disability"). The remaining number of eligible patients with disabilities was 11,998, with 11,113 adults and 855 pediatric patients. Of the eligible patients, 33% reported more than one disability, with a mean number of 1.45 disabilities (SD = 0.76, Range = [1, 7]).

Description of patients' disability responses

In describing the disability type, the greatest number of adults reported "lower limb disabilities" (26%), followed by "chronic conditions" (24%). Table 1 includes a full description of the patients' responses and the percentage of patients reporting each category. For the disability narrative category, the greatest number of adult patients listed an activity they have difficulty with (56%), followed by a diagnosis (21%) and a body part (19%). For pediatric patients, the greatest number of patients reported developmental disabilities (43%) followed by learning disabilities (15%) for disability type. For the disability narrative type, the vast majority of pediatric patients listed a diagnosis (83%) followed by describing an activity with which they had difficulty (18%).

Description of disability type by disability narrative category

We compared how patients who identified within different disability types then described their disability narrative category. We found that within the disability type categories, patients did so by using different disability narrative categories. For example, the majority of adult patients who reported mental health (97%), learning (76%), cognitive (72%), and hearing disabilities (65%) (disability types), did so by listing a diagnosis (disability narrative). In contrast, only 13% of those with lower limb disabilities described it by a diagnosis. Instead, more people described their lower limb disability by stating an activity they were not able to do (53%) or naming a body part (31%). Over half (67%) of those who described their disability with an activity, did so for lower limb disabilities (See Table 2).

Similarly, for pediatric patients, descriptions of their disabilities