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Exploring Issues Relating to Disability Cultural Competence Among Practicing Physicians

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Abstract

Background: Many factors contribute to the well-recognized health care disparities experienced by persons with disability, including failure of physicians to understand the lives of individuals with disability. Disability cultural competence considers physicians' ability to meet the social, cultural, and linguistic needs of this population.

Objectives: To assess physicians' understanding of disability cultural competence and attitudes towards patients with disability.

Methods: Qualitative analyses of open-ended individual interviews averaging 41 minutes with 20 Massachusetts physicians from 5 different subspecialties, in practice for 8-51 years. Interview recordings were transcribed verbatim for conventional content analysis.

Results: Most participants defined disability using medically-focused concepts rather than concepts that recognize how social factors contribute to disability. All participants used disability culturally-competent language, such as "person-first language," at some points throughout their interviews. However, most participants also employed language that is now considered unacceptable or archaic, such as variations on the word "handicap," "wheelchair-bound," describing persons with disability as "suffering," and calling persons by their health condition (e.g., "COPDer"). Participants mentioned persons with mental illness and intellectual disability as particularly challenging, especially around communication and performing even routine tests or examinations. Recommendations for improving care included better listening to patients with disability and seeking their views about their care.

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Conclusions: In this exploratory study, most participants used language that is considered disability culturally competent at times but also employed many terms and concepts that are considered outdated and may be troubling to some persons with disability.

Keywords

disability; cultural competence; attitudinal barriers; language; Americans with Disabilities Act

Introduction

Persons with disability experience disparities in their health care, including in screening and preventive services,¹ treatment of major health conditions,² and reproductive health care.^{3,4} Provider-level factors contributing to these disparities include inadequate knowledge about disabling conditions,⁵ insufficient scientific evidence to guide care for persons with disability,⁶ and inaccessible medical diagnostic equipment.⁷ Another possible contributor to health care disparities is physicians holding erroneous assumptions about the values and expectations of individuals with disability, assumptions that mirror widespread, stigmatized societal views about disability.^{8,9} Such inaccurate perceptions suggest that many physicians lack the cultural competence required to care effectively for persons with disability. Cultural competence is defined as the “ability of providers and organizations to effectively deliver health care services that meet the social, cultural, and linguistic needs of patients.”¹⁰ This concept has attracted considerable attention in the context of race and ethnicity, but considering cultural competence in caring for persons with disability is now earning recognition.⁹ This recognition is particularly apparent among subgroups of persons with certain disability types who have themselves coalesced to assert a unique cultural identity, such as persons who are Deaf, persons who adhere to the principles of disability rights and independent living, or athletes in the Special Olympics.

However, several factors might impede physicians from appreciating cultural competence in the context of disability. Importantly, disabilities are diverse and no single definition of disability encompasses this heterogeneity. Different societal sectors, notably including entitlement programs, use their own specific definitions of disability (Table 1). Physicians play central roles in making administrative disability determinations (e.g., for income support) using these definitions; these administrative assignments as “disabled” may sometimes conflict with patients’ self-perceptions.

Similarly to other populations that experience disparities, disability identity can carry cultural connotations.¹¹ The cultural understanding of disability has moved from the “medical model,” which originated in the 19th century,¹² to the “social model” in the 1960s.¹³ The medical model views disability as “abnormal” and something to be remedied, isolating persons with disability and ignoring the wide continuum of human functioning.¹⁴ Instead, the social model view disability as a civil rights issue, with barriers imposed on persons by inaccessible physical environments and stigmatized societal attitudes. This viewpoint catalyzed the 1990 Americans with Disabilities Act (ADA), the leading disability civil rights law. The ADA employs “person first” language – “persons with disability” rather than “disabled persons” – to recognize the primacy of the person, not the disability.¹⁵

Physicians may not be aware of these changes in the conceptualization of disability, since their continuing roles in administrative disability determinations remain embedded in the medical model. Therefore, physicians may be unaware of the imperative to consider cultural factors in caring for persons with disability.

The purpose of this study was to explore how physicians define disability and how their language and attitudes align with current notions of disability cultural competence. This exploratory study involved qualitative analyses of in-depth interviews with 20 practicing physicians. A 2016 review from the Agency for Health Care Research and Quality about improving health care disparities for persons with disability highlighted the role of improving disability cultural competence,¹⁶ but little is known about physicians' perceptions and practices concerning this concept.

Methods

The Massachusetts General Hospital (MGH)/Partners HealthCare Institutional Review Board (IRB) approved this study. The IRB viewed willingness to participate after interview procedures were explained as indicating implied informed consent.

Participant Recruitment and Interview Procedures

We initially aimed to complete 25 interviews with practicing physicians. We sought physicians within 5 specialties that frequently encounter patients with disability or accommodation needs: primary care (general internal medicine and family practice), rheumatology, neurology, obstetrics/gynecology (OB/GYN), and orthopedics. We obtained contact information for a random sample of physicians practicing in Massachusetts in the above specialties (n = 520) from SK&A Healthcare Databases (Irvine, CA). We excluded fellows, residents, and trainees from this sample. All physicians affiliated with Partners HealthCare (PHC) were also excluded due to concerns about response bias and administrative considerations (remaining n = 365). PHC policy prevents researchers from paying honoraria or incentive payments to individuals employed by PHC. Physicians were randomly selected for contact via email with telephone follow up. Missing and inaccurate contact information in the data source made it difficult to assess non-participation rates; it is also unclear whether intended recipients ignored or did not receive the recruitment emails. We subsequently could not reach two physicians who had earlier agreed to participate. We stopped recruitment after 20 completed interviews because no new information emerged from additional interviews (i.e., we had reached data saturation).¹⁸

Interview Protocol

We developed an open-ended interview protocol suitable for telephone administration that addressed various topics raised in caring for persons with disability (supplementary appendix). The interview protocol was developed based on concerns frequently described by people with disability in descriptions of their quality of care. Our conceptual framework posited that the following factors affect the health care experiences of patients with disability:⁶ professional and personal attributes of physicians; physical environment of health care setting; professional and personal attributes of other health care personnel in the

care setting; policy factors, including health insurance; and broader societal environment. The protocol was designed to gain the perspective of physicians on these issues in a non-confrontational manner. To explore the language participants used to refer to disability and their attitudes about disability, we examined all responses, regardless of topic, given that language and attitudes may be interpreted across all interview responses. Here, we also focus on responses to two questions explicitly intended to highlight definitional issues:

- “When you hear the phrase ‘person with a disability,’ what comes to mind?”
- “How do you define disability?”

In addition, we examined responses to a broad question seeking global recommendations for improving care for persons with disability.

One interviewer (L.I.I.) conducted and audiotaped all 20 telephone interviews, which averaged 41 minutes in length. Only L.I.I. and the participant were present during the interview, no repeat interviews were conducted, and we did not send transcripts to participants post-interview. We offered participants \$100 (4 interviewees refused payment, offering their participation as a research contribution). A professional transcription service transcribed the audio-recorded files verbatim. N.A. compared recordings to their transcripts, making minor corrections. The first three interviews served as pilot interviews. Since only minor changes were subsequently made to the interview protocol, we included these first three interviews in the analysis.

Research Team and Reflexivity

Items consistent with the COnsolidated criteria for REporting Qualitative (COREQ) Research checklist are reported here. L.I.I. conducted all interviews. The research team included L.I.I. (MD, MSc, professor, health services researcher) and N.A. (undergraduate research assistant) based in Boston, and E.G.C. (PhD, professor, survey scientist) and J.R. (MPH, project manager) at University of Colorado School of Medicine in Denver. Three researchers identified as female and one as male. All researchers were experienced in qualitative research methods. The interviewer (L.I.I.) has extensive background in conducting qualitative descriptive research interviews (over 150 individual research interviews conducted with external funding from NIH and foundation grants). Given that she has been a member of the medical and research community in Massachusetts for more than 30 years, it is not surprising that 4 of the randomly recruited participants were acquainted with her. However, she has not had contact or correspondence with them for at least several years. The study participants were informed that the interview goals were to learn about their experiences with and perceptions of caring for persons with disability. However, they did not have any other prior knowledge of the study. The research team did not have personal biases that may have influenced the outcomes of the study.

Analysis

We used conventional content analysis,¹⁹ a type of qualitative descriptive analysis,^{20,21} to identify findings from interview transcripts without overinterpreting the results. We performed analyses upon completing all 20 interviews. After reviewing manuscripts several times, we generated coding categories to facilitate analysis. N.A. initially coded the

transcripts using word processing software. For such descriptive qualitative studies, our research team has found manual sorting of data is more efficient than qualitative software (e.g., NVivo, Atlas.ti, etc). The Boston research team (L.I.I. and N.A.) met frequently to reach consensus on coding categories and findings. Independently, the Denver research team (E.G.C. and J.R.) reviewed transcripts and identified major findings. The four researchers reached consensus about the domains and coded themes over conference call, including decisions about which themes and interpretations were consistent across the data. Below, we sometimes indicate the number of interviewees who reported themes to avoid vague terms (e.g., “some,” “several”). We do not show percentages given our small sample and sampling procedures.

Results

Table 2 presents demographic information about the 20 participants. Our sample included equal numbers of men and women, with a mean (standard deviation) number of years in practice of 27.4 (12.5). Of the 20 participants, 16 physicians practiced in academic centers. We looked at four major domains, each containing several themes, concerning disability definitions and cultural competence issues.

How Physicians Define Disability

Responses to the question about how participants define disability generated 3 themes: (1) limitations in one or more major life activities indicate disability; (2) anyone who needs an accommodation has a disability; and (3) patients themselves identify whether they have disability (Table 3). Some respondents said they did not know a legal definition of disability, while several participants considered regulatory definitions (Table 1).

Comments from one rheumatologist exemplified the theme relating to activity limitations: disability occurs when someone “has difficulty with activities and daily living.” A neurologist defined disability as “a limitation of one’s physical or emotional ability, which prevents that person from being competitive with the general public in any aspect of life...”

Other participants defined disability based on need for accommodations. An internist indicated that persons with disability need “certain adjustments when I talk to them or think about how to take care of them.” An orthopedist noted, “I’m thinking someone for whom I’m going to have to make extra special accommodation, although I try to see everybody as having their own issues.”

Yet other participants indicated that patients themselves could or should define disability. According to a neurologist, “a person should be the one to decide if they’re disabled or not.” In a related comment, an OB/GYN physician noted that disability can occur when people “suffer from extreme stigma.”

Several participants incorporated regulatory or legal aspects in their definitions. An internist raised Social Security Administration definitions (SSA, Table 1), noting he had received no formal training in such evaluations but he was familiar with “disability in the rigorous way as defined by SSA...” A neurologist alluded to definitions linked to worker compensation

assessment: “So if previously you had a job that was physical, and now you’ve hurt your leg and you can’t do it anymore, that’s a disability ... [but] if your job was seated, and you didn’t use it anyway, well, then now it’s not a disability.”

Word Choices When Referring to Disability

The second domain considered the words participants used to refer to disability that might reflect cultural competence. This domain encompassed 6 word choice themes: (1) different permutations of “normal” and “abnormal” functioning; (2) “handicap” to describe either patients or aspects of accessibility; (3) “suffering from” some condition; (4) “wheelchair-bound” and other outdated terms; (5) language that is not “person-first”; and (6) language consistent with current U.S. general views of disability cultural competence (Table 4).

At the outset, it is important to note that almost all participants used language considered disability culturally competent at some points during their interviews. Examples include “people with disabilities,” “patients who are also developmentally delayed,” and “patients who have trisomy 21.” However, participants also commonly used less culturally competent words and phrases.

Participants frequently used “normal,” “abnormal,” and “abnormalities” to describe various aspects of disability. An OB/GYN physician described disability “as anything that really takes somebody out of what I would expect the very basics of general, normal human functioning ...” In contrast, one orthopedist observed, “There aren’t ‘normal’ and ‘abnormals’ for me. Everybody comes in, and they got a problem.”

Interviewees used “handicap” in various contexts. A neurologist referred to “people with intellectual handicaps” and “hereditary handicaps.” Another neurologist used “mentally handicapped” to describe mental illness and “pedal handicaps” to describe physical disability. Participants used variations of “handicap” to describe accessibility accommodations, especially relating to parking.

Participants used variations of “suffering from X” to describe disability. An OB/GYN physician commented on “women who suffer from anorexia or bulimia.” Another common phrase was “wheelchair-bound.” An OB/GYN physician recalled: “the one woman I remember who was wheelchair-bound didn’t need a weight.” One physician used “mental retardation” to describe patients with intellectual disability.

Almost all participants used language that was not person-first, such as “disabled people” and “schizophrenic patient.” Some participants used grammatical constructions that equated persons with their condition. For example, an internist referred to “severe COPDers”, and a family practitioner mentioned “patients who are Down syndrome.”

Attitudes Towards People with Disability

The third domain involved attitudes, including 3 themes: (1) patients with disability are challenging; (2) disability can stimulate pity or other emotions; and (3) physicians can make erroneous assumptions about patients with disability.

Participants described patients with disability as more challenging than other patients. An orthopedist observed that patients with disability “require more resources, and some of those resources are the energy and dedication that’s required from the people who care for them...” An OB/GYN physician suggested that the extra resources required might deter physicians from seeing patients with disability: “It’s just too much of a hassle for ... the person in private practice who’s got a small office ...” Participants singled out patients with mental illness as especially challenging. A neurologist described a disruptive patient who repeatedly called the clinic, saying that clinicians “get very upset by them, understandably, and I got upset too.”

Participants highlighted challenges involving intellectual disability. An OB/GYN physician described an encounter with a patient with intellectual disability: the physician “never even bothered trying to touch her. I put her under sedation because there would be no way for me to explain to her what I was doing.” An internist described a patient with intellectual disability “who really needs a blood draw but will not allow it... Her mother, who’s her guardian, says ... ‘just tie her up ... That’s what they do to the ER ones ...’ The internist refused to do that and turned to colleagues, but “they didn’t have any other ideas.”

A rheumatologist summarized the reaction of physicians when they see patients with disability on their schedule: “They groan or they are not as excited... getting through the visit is going to take longer than they’ve been assigned or allotted.”

The second theme involved physicians expressing pity or decrying the patient’s disability. For example, a neurologist described ““a lot of awful situations where [patients are] quadriplegic, or quadriparetic, that they can’t even use one or two fingers to indicate yes or no ...” One internist referred to a patient with “pretty horrible schizophrenia,” while another internist described a patient’s obesity as emotionally “hazardous.”

Finally, physicians acted upon assumptions about patients with disability. One neurologist recounted speaking to the caregiver instead of directly with the patient who had an intellectual disability: “It takes one or two times when that person tells you that they’re very upset about that before you realize how big a mistake that is and how important it is to engage them in the conversation...”

Other assumptions concerned the independence and functioning of people with disability. A neurologist observed, “I have found the more disabled a patient is the more likely that person is to be independent than the person who’s had some mild, acute issue and wants everything done for him or her ...” An OB/GYN physician described one patient who had a personality disorder and “made my life absolutely horrific...” The patient had pelvic pain and wanted surgery that the physician believed was not indicated. The physician “was trying to reason with her, which was incredibly difficult because she wasn’t able to reason...” The end result was a successful surgical operation for the patient.

A recurrent assumption involved the sexual and reproductive health of patients with disability. An OB/GYN physician, in practice for 29 years, stated that sexual activity negatively “correlates with the level of impairment.” Additionally, an OB/GYN physician discussed state regulations that require institutionalized women to receive yearly Pap tests,

recommending more flexibility in state regulations because it is unnecessary and even “criminal” to require this test for women with intellectual disability.

Recommendations for Improving Disability Understanding

Finally, responses to a global question about recommendations for improving quality of care fell into 2 themes related to disability cultural competence: (1) learning from clinical experiences that dispel myths about living with disability; and (2) listening to patients to avoid erroneous assumptions.

A family practitioner observed that doing home visits with patients with disability “changed how I thought about practicing.” This participant described home visits to an elderly man who was blind but nevertheless measured his own blood sugar: this fact did not “come out until I went to the house and saw how he was doing things and realized the blood sugars weren’t actually being done by the visiting nurses, it was ... being done by him.”

Physicians also recommended asking the patients about their preferences to avoid making erroneous assumptions. A rheumatologist suggested:

... It’s helpful to ask the patient how we could do better.... Let’s say a patient’s in a wheelchair... Some of the exam is not done in the usual way if the patient is paraplegic or whatever. ... I don’t think we know what works best for the patient in terms of performing the physical exam, respecting their dignity, not making assumptions about what they can and cannot do, what they can and cannot feel.

Discussion

Improving cultural competence has become one core strategy for reducing health care disparities for various subgroups that experience inequities, including persons with disability.²² Section 5307 of the Patient Protection and Affordable Care Act of 2010 calls for the “cultural competency, prevention, public health proficiency, reducing health disparities, and aptitude for working with individuals with disabilities training for use in health professional schools and continuing education programs.”²³ This qualitative study suggests that gaps remain in the disability cultural competence of practicing physicians.

Not surprisingly, most participants defined disability using medical model concepts or requirements of income support programs. Few participants recognized the effects of social stigma embedded in the final component of the ADA’s 3-part definition, which aimed to protect people against prejudice and discrimination arising from erroneous assumptions about impairments.²⁴ Disability cultural competence requires appreciation of social model precepts,²⁵ which recognized patients’ rights to seek care that meets their expectations and values.

Participants frequently used language that would not be considered disability culturally competent, including variations of “handicap,” “wheelchair-bound,” and “suffering” from a condition. “Handicap” originates from an archaic English phrase conveying defeat, where a person who lost a game finished with a “hand in his cap.”²⁶ “Handicap” had been used in federal laws relating to disability for many years and is still used for parking placards,

although it has been replaced by “disability” in most other contexts. The phrase “suffering from” implies affliction, fear, and pity,²⁷ while “wheelchair-bound” suggests confinement and dependency. Instead of the “bound” metaphor, persons prefer simple subject-verb language, being called “wheelchair users.” Of course, as in other minority groups, some persons with disability self-describe using historically fraught terms that raise concerns if applied by persons outside the disability community.

The term “mental retardation” has also been replaced with “intellectual disability” in federal laws and regulations in recognition of the negative connotations that the term carries.²⁸ This change was mandated by Rosa’s Law of 2009, which stipulated that references to “mental retardation” in health and education codes be changed to “intellectual disability.”²⁹ *The International Classification of Diseases, Tenth Revision, Clinical Modification* (ICD-10-CM) has replaced codes for “mental retardation” with codes for “intellectual disabilities,” prefixed with “mild,” “moderate,” “severe,” “profound,” “other,” or “unspecified.”³⁰

Cultural constructs are not uniform within the U.S., let alone worldwide. For example, although the ADA uses “person-first language” – “persons with disability” – some have argued that putting “disability” second implies shame or lack of pride in “disability identity.”³¹ In some European countries, “identity first” – “disabled person” – is the preferred phrasing. However, embedded within language are concepts that convey powerful socially-mediated constructs. Person-first language recognizes the full person and that disability is only one component of an individual’s identity.³² Similarly, phrases such as “severe COPDers” and “patients who are Down Syndrome” suggest that persons define themselves by their health conditions, which is not typically the case.³³ Table 5 shows alternative phrases that reflect culturally competent language.¹⁴

Our findings also suggest that certain categories of disability – particularly intellectual disability and mental illness – raise challenges, especially around meaningful communication. Participants described addressing a caregiver rather than the patient and wanting to sedate patients to perform routine procedures. Physicians commonly assumed that patients with intellectual disability cannot make responsible decisions about their care,³⁴ although techniques exist that can support their decision-making.³⁵ Approaches also exist to facilitate interactions with persons with serious mental illness.³⁶ A patient’s right of self-determination makes it critical to communicate with the patient and not assume that physicians can perform procedures without proper communication and informed consent.³⁷

This study has several limitations, most importantly concerning generalizability of our findings. Given that we excluded Partners HealthCare physicians, our results do not generalize to physicians across Massachusetts or nationwide. Attitudes and approaches could vary across regions of the U.S. Because of small numbers, these results also do not generalize to each individual specialty and practice type. Furthermore, the study was not designed to contrast perceptions across specialties. Given that our respondents had averaged 27 years in practice, and the impetus to introduce disability issues into medical school curriculum only began in the past 15 years, the respondents may not reflect attitudes among younger physicians. Another potential limitation is that 4 of the randomly recruited interviews had an informal acquaintance with the interviewer, though they have not had

contact in several years. However, concerns about positive response bias were reduced given that all 4 participants demonstrated erroneous assumptions about disability. Nevertheless, these participants may possibly have felt more comfortable sharing their perception of disability, given their prior acquaintance with the interviewer. Despite these limitations, our findings are consistent with reports from patients about their perceptions of care and therefore have face validity. Qualitative methods and in-depth interviews are also an efficient methodology to explore language choices and attitudes.

With growing numbers of Americans with disability, now estimated at approximately 57 million persons, most physicians can expect to see persons with disability in their practices.³⁸ This population is diverse, with each individual having their own preferences and values. Nonetheless, improving care for persons with disabilities is a public health priority.³⁹ Major recommendations from this study are that physicians should listen more to their patients with disability, refrain from using language that is archaic or not culturally competent, reduce erroneous assumptions that could compromise quality of care, and proactively solicit patients' feedback. In a review of the literature on the cultural competence of health care providers in caring for persons with disability, the Agency for Healthcare Research and Quality reported a paucity of interventional studies, the majority of which focused on changing providers' attitudes about mental illness.¹⁶ This study has identified a variety of issues related to disability cultural competence that may emerge in the clinical setting, suggesting the need for a more rigorous approach to interventions aimed at improving disability cultural competence. Improving disability cultural competence could increase equity of care for persons with disability and maximize the likelihood that they receive care consistent with their needs, expectations, and values.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1**Models of Disability and Legal and Policy Definitions**

Source	Definition of Disability
Models of disability	
Medical model	“The medical model views disability as a feature of the person, directly caused by disease, trauma or other health condition, which requires medical care provided in the form of individual treatment by professionals. Disability, on this model, calls for medical or other treatment or intervention, to ‘correct’ the problem with the individual.” ¹⁷
Social model	“The social model of disability, on the other hand, sees disability as a socially created problem and not at all an attribute of an individual. On the social model, disability demands a political response, since the problem is created by an unaccommodating physical environment brought about by attitudes and other features of the social environment.” ¹⁷
Bio-psycho-social-environmental model (WHO model)	“‘Umbrella term for impairments, activity limitations or participation restrictions,’ conceiving “a person’s functioning and disability ... as a dynamic interaction between health conditions (diseases, disorders, injuries, traumas, etc.) and contextual factors,” including the social, attitudinal, and physical environments and personal attributes.” ¹⁷
Disability civil rights laws	
Americans with Disabilities Act (ADA), 1990	“§3(2) “The term ‘disability’ means, with respect to an individual—(A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (B) a record of such an impairment; or (C) being regarded as having such an impairment.”” ¹⁸
ADA Regulations (28 CFR Part 36, §36.104)	““Major life activities include such things as caring for one’s self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working.” ¹⁸ To be substantially limited, an individual’s important life activities must be “restricted as to the conditions, manner, or duration under which they can be performed in comparison to most people.”” ¹⁸
Income support programs	
Social Security Administration	““Inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment(s) which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months.”” ¹⁸
AMA Guide 6 th Edition	<i>Disability</i> is “activity limitation and/or participation restriction in an individual with a health condition, disorder or disease” ¹⁹ <i>Impairment</i> is “a significant deviation, loss or loss of use, of any body structure or body function in an individual with a health condition, disorder or disease” ¹⁹ <i>Impairment rating</i> is “a consensus-derived percentage estimate of loss of activity, which reflects severity of impairment for a given health condition, and the degree of associated limitations in terms of activities of daily living (ADLs)” ¹⁹

References

¹⁷. *Towards a Common Language for Functioning, Disability, and Health: The International Classification of Functioning, Disability, and Health (ICF)*. Geneva, Switzerland: World Health Organization; 2002.

¹⁸. Iezzoni LI, Freedman VA. Turning the disability tide: the importance of definitions. *JAMA*. 2008;299(3):332-334.

¹⁹. Rondonelli RD. *AMA Guides to the Evaluation of Permanent Impairment, Sixth Edition*. Sixth. (Genovese E, Katz RT, Mayer TG, Mueller K, Ranavaya M, eds.). American Medical Association; 2007.

Table 2

Characteristics of Interviewees

N = 20

Characteristic	
Age: mean (S.D.) years	53.5 (11.7)
Age range: years	38-76
Gender: n	
Male	10
Female	10
Race: n	
White	18
Nonwhite	2
Hispanic ethnicity: n	1
Specialty: n	
Internal medicine	7
Family practice	1
Rheumatology	2
Neurology	6
Obstetrics/gynecology	2
Orthopedics	2
Time in practice: mean (S.D.) years	27.4 (12.5)
Type of practice: n	
Hospital-based	16
Private, not hospital-based	4

Table 3

How Participants Define Disability

Specialty	Years ^a	Quotations
Subtheme: limitations in one or more of major life activities represents disability		
Internal Medicine	23	"...disability is where they are completely dependent on somebody, like a caregiver"
Internal Medicine	34	"Any physical or cognitive characteristic or that it appears someone's ability to function optimally or the way they want to be functioning."
Internal Medicine	16	"There are physical disabilities, there are mental, intellectual disabilities. Some of the intellectual disabilities maybe include the learning disabled, dementia patients, major depression where it's a chronic-type issue, schizophrenia, bipolar disorder. We've had several patients with hallucinations, some variant of psychosis, whether that's tied to post-traumatic stress and other disorders. For physical disabilities, there's certain patients who suffer from chronic pain and they're disabled. Different setting, different types of problems, but their bodies, their lives, are just as disabled."
Rheumatology	14	"...someone has pain or has a limited range of motion in their extremities. That's why they cannot work or function as normal."
Rheumatology	35	"I generally have sort of a broad definition of it being anything the patient feels they can't do and want to do, especially if they used to be able to do it. So I don't know the legal definition, but that's how I think of that."
Family Medicine	8	"...somebody whose capability for functioning in what would be considered a normal day to day environment is impacted by a physical problem outside of their control, or a mental problem outside of their control that makes it hard for them to function in that way."
Neurology	11	"...someone who has some impairment in the five senses or an impairment in their ability to access resources... Someone who has some functional impairment."
Neurology	12	"The definition was on my pain boards... I can't believe I forgot all this stuff... You can't do your job to have a livelihood, or you can't-- it was activities of daily living...Toileting, eating, having a job, and then if your disability made it so you couldn't do something that you previously did, it was a disability. It's your problem."
OB/GYN	29	"...someone who has either a physical or mental handicap that impairs their ability to do what they want to do. ..."
Orthopedics	48	"Someone who is limited in a way that-- significant's a tough word-- but impact on their function... somebody who is... a couple of standard deviations off the mean enough so it makes a difference in their life."
Subtheme: anyone who needs an accommodation has a disability		
Internal Medicine	19	"...they might need some extra care. But I always say it's a unique person. We are all different. And we have all our little specialties. And so somebody with a disability, they might need just more adjustments to the regular life we lead."
Neurology	43	"Well for my fields, persons who are dependent on equipment for locomotion. Who are handicapped equipment dependent, whether it be wheelchair, rolling walker, cane, and then people who are also cognitively impaired."
Orthopedics	31	"...someone who requires extra help or accessible—or special accommodation...."
Subtheme: patients themselves identify whether they have disability		
Internal Medicine	21	"I think that disability is defined in the eyes of the patient."
Internal Medicine	25	"...disability might be defined from the outside, from someone defining it for someone, but it also would be defined by that person. There are people who can't see, who can't hear, perhaps both, who are working and earning money, and have a home, and have a family, and are fully functional. And then there are people who, I don't know, perhaps have an injured knee, osteoarthritis of the knee, have some trouble getting around, and have defined themselves as disabled. So as far as an absolute definition, that's really tough, and it bears thinking about."

^aYears in practice

Table 4

Language Used to Describe Disability

Specialty	Years ^a	Quotations
Subtheme: variations of words “normal” and “abnormal”		
Internal Medicine	25	“Well, this is a subgroup in the psychiatry department, which is, I guess, new, that’s designed to help primary care doctors care for their patients with neurologic abnormalities, in particular patients who I think have severe cerebral palsy...”
Rheumatology	14	“That’s why they cannot work or function as normal.”
Family Medicine	8	“A number of patients who have long standing issues, Cerebral Palsy or other structural abnormalities of the brain.”
Neurology	51	“I’ve had patients who have come and the interpreter, or whatever the term is for the individual who bridges the gap between the deaf and those of us who hear normally...”
Orthopedics	48	“So in terms of the amount of disability that people have when they come to see me, some of them are functioning absolutely normally.”
Subtheme: variations of “handicap” to describe either patients or aspects of accessibility		
Internal Medicine	40	“...we need bigger clinic rooms that are accessible for handicap folks.... But I think if we just had room, the right exam tables, bathrooms that are handicapped accessible...”
Neurology	31	“...the clinic is set up for handicap access.”
Neurology	11	“We have handicapped restrooms that are large enough to accommodate wheelchairs.”
Neurology	41	“...we had a lot of patients who are handicapped and therefore needed to be on stretchers or in wheelchairs.”
Neurology	43	“I think that handicap people should be taken care and live their lives in the least restrictive environment possible...”
OB/GYN	29	“So there’s certain kind of stipulations for doorway widths, handicap accessibility...handicap accessible bathrooms, and we have several kind of handicap accessible exam rooms.”
Orthopedics	48	““They’re very physically handicapped...”
Subtheme: variations of “suffering from” some condition		
Internal Medicine	16	“For physical disabilities, there’s certain patients who suffer from chronic pain and they’re disabled.”
Internal Medicine	40	“suffer from really major medical issues...”
Subtheme: variations of “wheelchair-bound” and other outdated terms		
OB/GYN	17	“So those patients are wheelchair-bound, and they don’t really have good cognition level, and so they are not making any decision for themselves.”
OB/GYN	29	“If we have somebody who’s truly confined, then we’ll bring in a second person and myself.”
OB/GYN	31	“The problem would be an obese patient who’s wheelchair-bound with a spinal cord injury or something, right?”
Neurologist	12	“When I see a patient, and they’re wheelchair-bound-- now, I would say half of, that’s a very rough estimate, but half of wheelchair-bound patients can transfer...”
Subtheme: language that is not “person-first”		
Internal Medicine	16	“There’s an awful lot of depression-type patients.”
Rheumatology	14	“...juvenile idiopathic arthritis patients... some pain patients... diabetic blind patients...”
Neurology	31	“...she, in fact, was a psychotic, and was paranoid, and inappropriate, and disruptive.”
Neurology	41	“I mainly see Parkinson’s, and Lewy body dementia patients, and some other movement disorders. ...the Parkinson patients, often they come quite disabled...”
Neurology	12	“...vision-impaired patient...”
Orthopedics	48	“...high-intensity disability group of patients.”
Subtheme: language consistent with current U.S. general views of disability cultural competence		

Specialty	Years ^a	Quotations
Internal Medicine	19	“...a lot of these patients have disabilities... I definitely have a few patients who have mental disabilities...”
Rheumatology	14	“So we do see a lot of kids with juvenile idiopathic arthritis... So we have children with lupus, with mixed connective tissue disease, or vasculitis... children with Lyme disease, especially if they have Lyme arthritis... we also see patients with pain amplification syndrome... kids with vision challenges... we have one child with Down syndrome and arthritis... And then for the parking garage also, there's access for people with disability...”
Neurology	31	“I certainly have a few patients, for instance, occasional patients who are deaf.”
Neurology	41	“A fair number of them are hard of hearing...”
Neurology	43	“Not every patient with MS has memory problems...”
Neurology	11	“...patients that have cerebral palsy...”
Orthopedics	31	“people who have had spinal cord injuries... also some people who are deaf...”

^aYears in practice

Table 5**Recommended Language**

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- Say “people with disability” instead of “disabled or handicapped people”
 - Say “people without disability” instead of “normal people”
 - Say “uses a wheelchair/mobility device” instead of “confined” or “wheelchair-bound”
 - Say “accessible parking” instead of “handicapped parking”
 - Say “patients with DISEASE” instead of “VARIANT OF DISEASE” (e.g., diabetics, asthmatics, COPDers, depressives, schizophrenics)
 - Say “intellectual disability” instead of “mentally retardation,” “mentally retarded”
 - State the nature of the disability instead of saying “defect/birth defect” or “deformed”
 - Avoid using “crippled,” “crip,” “gimp,” recognizing that some persons with disability might apply these words to themselves
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