Abstract

Introduction: Millions of American patients have a disability, and their health care outcomes depend on the attitudes of their health care providers towards persons with disabilities. Overly negative health care provider attitudes lead to significant misunderstandings about what it means to have a disability, inappropriate assumptions, and poor care. However, very few medical schools teach about disability.

Methods: We developed a preclinical medical student curriculum that addresses the complexity of disability, focusing on health care disparities and bias. Our curriculum was designed with significant input from people with disabilities and was constructed from their perspective. In addition to didactic and discussion sessions on disability history, models of disability, and health disparities, we include a discussion panel with community members who have a disability.

Results: The curriculum has been effective at promoting discussion and is well received by students. When rating the relevance to future clinical practice, students gave the curriculum an average of 3.9 on a 5-point Likert scale (1 = poor, 5 = excellent). The majority of students commented that the community involvement in the session was the most meaningful aspect.

Discussion: It is possible to integrate community-driven discussions on the social context of disability into traditional medical school preclinical curricula, and students find it valuable to their education.

Keywords
Cultural Competency, Empathy, Patient-Centered Care, Disability, Diversity, Disparities

Educational Objectives

By the end of this session, students will be able to:

1. List key events in the history of US disability policy.
2. Differentiate between the medical and social models of disability.
3. Describe the health and health care disparities associated with having a disability.
4. Engage with a panel of individuals living with disabilities.
5. Describe the complex relationship between disability and health.

Introduction

According to the World Report on Disability,1 over a billion people live with a disability, including 54 million Americans.2 These numbers are expected to rise as the average age3 and body mass index4 of the US population continue to increase.

Many studies and government reports provide evidence for incongruent health care between people with disabilities and their nondisabled peers. It has been shown that people with disabilities are less likely to receive acute condition treatment5; preventative care, including gynecologic care6; and counseling on contraception, smoking cessation, and obesity.7
Disparities have been associated with poor health care provider understanding of disability, as misunderstandings lead to inappropriate assumptions and a decrease in quality of care. To begin to address disparities in care, health care professionals need to receive improved education on disabilities. In fact, Section 5307 of the Patient Protection and Affordable Care Act states that a model disability curriculum should be developed that addresses “cultural competency, prevention, public health proficiency, reducing health disparities, and aptitude for working with individuals with disabilities.” While policy and literature alike are increasingly recognizing the importance of addressing attitudinal barriers, only a few health care training programs have begun to include disability topics in their curricula.

Several published disability curricula have been developed with the aim of teaching clinical skills. While this is very important, it is also important to explicitly address disability culture and disparities. Learning about the disability rights movement and disability culture puts disability in a greater context and redefines disability to include important social components. The social model, which states that impairments are disabilities just to the extent that the appropriate accommodations are not available for them to be included, is in contrast to the more traditional medical model of disability, which implies that disabilities are a function of the individual and are to be cured. If disability culture and disparities are not discussed during medical training, the more traditional medical model is reinforced, and the health and health care disparities are perpetuated.

A general overview of our curriculum has been described previously. The development and implementation were enhanced by significant input from people with disabilities who provided their narratives and insight into disability culture. Including community members in medical school curricula is thought to be beneficial in that it promotes empathy and moral development and increases the perceived value of patient-centered care.

There are two main components to the full disability curriculum: (1) integrating disability topics into basic science instruction, specifically, our genetics course, and (2) conducting a stand-alone disability session during our Improving the Public’s Health course. While not included in this publication, a sample integrated day would include lectures on translocation and nondisjunction followed by a 30-minute tutorial on Down syndrome genetics counseling and a 60-minute discussion with individuals who have Down syndrome. Other disabilities we have highlighted include Williams syndrome, achondroplasia, and osteogenesis imperfecta. These discussions provide students the unique opportunity to interact with disability advocates as well as with community members who have disabilities.

Herein, we describe the stand-alone disability session, which is part of our 3-week Improving the Public’s Health course. This 2.5-hour session is designed to help medical students reflect on their own experience with disability while learning about historical and cultural context. Through discussions between people with disabilities, faculty who study disability, and other medical students, we aim to help students better understand disability and reflect on ways they may best reduce the health care disparities experienced by people with disabilities.

**Methods**

Two months prior to the scheduled session is a good time to contact local disability organizations to find four participants for the panel. While we realize that local resources may differ, we have included a list of organizations we have worked with in the past (Appendix A). We found that contacting local disability organizations, rather than patients, enhances the curriculum because the speaker is more likely to be trained and engaging and the students are more likely to learn about the advocacy agenda for the disability organization, both locally and nationally, in addition to hearing a single story. To provide a more comprehensive perspective on disability, we also found it important to invite participants with a variety of disability types (e.g., sensory, physical, intellectual, acquired, and congenital). All organizations we contacted were willing and eager to aid in speaker identification.

Each panelist received a list of questions prior to the session (Appendix B), which were used as discussion prompts by the faculty facilitator. Distributing questions to the panel ahead of time allowed participants,
especially those with communication and/or cognitive disabilities, to formulate responses and participate as much as possible.

In order to help students begin to think about their opinions regarding disability topics, we distributed a nine-question survey (Appendix C) for students to complete before the session. The survey questions were written by disability scholars and validated using two focus groups of five second-year medical students (N = 10). Focus groups were asked to take the survey in the presence of a session instructor and to describe their perceived meaning of the questions. This survey validation process was determined to be exempt by the Mayo Clinic Institutional Review Board.

The survey was distributed 3 days before the session and closed the night before the session so that responses could be aggregated and incorporated into the didactic session. For the open-text question, the instructors read the responses and made note of common ideas, which were then categorized by theme and distributed to the students. Incorporation of all responses within the slides of the didactic presentation (Appendix D) ensures that everyone’s voice is heard, even if someone chooses not to contribute to the live discussion.

The 2.5-hour session can be facilitated by one faculty member with experience in disability studies. During the first hour, you should review and discuss slides 1-26 of Appendix D. Then, the community member panelists should be invited to the front of the room for a 1-hour facilitated discussion. The class should then break into small groups (eight to 10 students) for a 10-minute discussion of their definition of disability. Next, bring the class back together for a large-group review of slides 27 and 28 (Appendix D). During this 10-minute review, you can invite the small groups to share what they came up with in their discussions and how their definitions might have changed due to the session. The session should close with a 10-minute recap of important takeaways from the day.

Results
This session was first implemented in 2012 and has run through four iterations with a total of 192 first-year medical students. Two faculty members have implemented the material, one who developed the material and another who later used the material. Both faculty had training and teaching experience in disability studies.

Overall, the disability curriculum has been well received. Each year, a postcurriculum questionnaire was completed by participating students, with 153 out of 192 students (80%) responding in 4 years. On a 5-point Likert scale (1 = poor, 5 = excellent), the curriculum received an average rating of 3.8 for the learning environment; 3.7 for the content, delivery, and style of the instructional materials; and 3.9 for the relevance to future practice.

When students were asked to comment on what they liked most about the course as a whole, 102 out of 192 students (53%) responded, and 65 out of 102 respondents (64%) commented that the community involvement in the course was most helpful.

Discussion
The most important part of the session development was the involvement of the local disability community. The disability rights movement has the slogan “Nothing about us without us,” and we found that adhering to this mantra served us well. The importance of including people with disabilities, especially disability advocacy groups who are familiar with the disability rights movement, cannot be overstated. The narratives that the community members brought to the curriculum were powerful, and several medical students who participated in the session in 2012 have recently commented, 4 years later, that these narratives have stuck with them throughout their training.

Inclusion of the class’s aggregate responses to the precurriculum questions was very effective at initiating discussion as disability is common and many incoming medical students already had significant experience with this population. Sharing these stories promoted learning and personal reflection.
Despite the overall success, this curriculum has a couple of limitations. The curriculum covers a very diverse and expansive topic in a relatively short period of time. With so many patients experiencing disability, it would make sense to lengthen the stand-alone disability session. We find that time restraints are the only limit to discussion, and many discussions continue after the end of the allotted time. For those institutions that do not have additional curricular time to discuss disabilities, it may be beneficial to have students complete a prereading. The succinct review of health disparities seen by people with disabilities by Iezzoni\textsuperscript{20} and the outline of the history of the disability movement by Shapiro\textsuperscript{21} are both interesting, quick reads.

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