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A Simple Disabilities Curriculum Improves Student Awareness of Disabilities

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Abstract

Learners sometimes struggle to communicate and empathize with patients with disabilities. Possible explanations for this include lack of access and exposure, emotional immaturity, and knowledge deficits. This often leads to a perception that disabilities lie outside the scope of primary care. We constructed a disabilities curriculum and embedded it within our existing third year curriculum. This curriculum is different from others because of the hands-on component in which the students are paired with a patient with a disability with the goal of transitioning patients successfully from pediatric to adult care. The disabilities curriculum also requires the students to listen to a lecture describing the healthcare challenges facing persons with disabilities. In addition, the students view a video showing proper etiquette toward patients with disabilities in medical environments. Finally, the students together visit the home of a young person with disabilities. The students complete the validated “Medical Student Attitudes towards Persons with Disabilities” survey before and after finishing the curriculum (see Appendix A). We compare those responses with another institution where the curriculum is not offered.

Introduction:

The proportion of people with disabilities is increasing both in the U.S. and worldwide.¹ Therefore, the AAMC has designated disabilities education as a priority for medical school education.² Their recommendation is that disabilities teaching be integrated into the overall curriculum. SUNY Upstate in partnership with the American Association of Physiatrists has developed a “Disability Toolkit” to enable medical schools to incorporate disability teaching.³ One 4-year medical school which has implemented many of the ideas presented in the Disability Toolkit is SUNY Upstate. That effort spans the entire 4 years with different experiences and assignments for students appropriate to their level of education.⁴

Our clinical campus, affiliated with Medical University of South Carolina in Charleston, is located in the upstate of South Carolina with a 561-bed hospital in a county of about 125 000 people. We are not aware of a disabilities curriculum followed at any other clinical medical school campus. In our case, we are limited to one year of on-site study, the third year only; therefore, we must integrate our curriculum into the busy third-year clinical schedule. Currently, our home institution has a disabilities curriculum involving the first and second years only.

Learners struggle to communicate and empathize with patients with disabilities for several different reasons. First, they may lack opportunities to interact with and learn about persons with disabilities. Since there is usually not a dedicated disabilities curriculum they often lack knowledge about specific disabilities as well as about disabilities in

general. Often, learners and providers believe that disabilities lie outside the scope of practice for primary care, making access to health care for persons with disabilities more difficult, and over-medicalizing common outpatient problems. Furthermore, the student often feels uncomfortable around persons with disabilities. Sometimes the patient has a disability involving intellect, speech, hearing, or sight, which directly interferes with communication. At other times a visible disability may distract or distress the learner. In addition, the learner sometimes struggles to show empathy to a patient who has a disability. Approaches to improving medical students’ empathy have been tried with varying success.⁵ We made use of gaps in care for patients with disabilities as an exercise to improve empathy in medical students.

One gap in care involves a subset of the disabilities community, youth with special health care needs (YSHCN), who are transitioning out of pediatric care to adult care. This transition often does not go smoothly or does not happen at all. This leads to morbidity and unnecessary healthcare expenditures in the form of emergency visits and hospitalizations. Therefore, transition for YSHCN is considered a priority for the American Academy of Pediatrics as delineated in its 2011 report.⁶ Medical students have been used for years at our clinical campus as “coaches” for YSHCN patients in transition with some success.⁷

The purpose of the disabilities curriculum is to train physicians who appreciate the challenges facing persons with disabilities, particularly as those patients interact with the healthcare system. We constructed a disabilities curriculum

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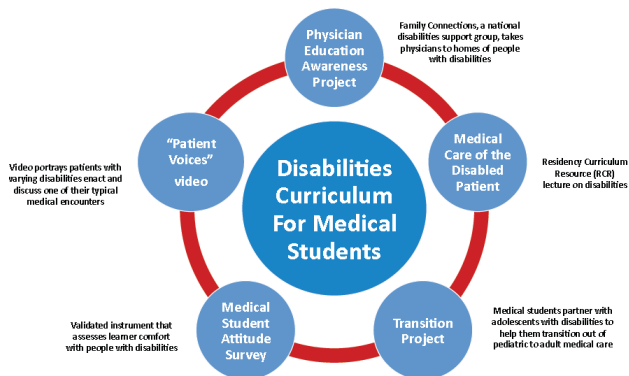
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and embedded it within our existing third year curriculum. There are 5 pieces of this curriculum spaced out over the year. Those 5 pieces are illustrated in the graph below



METHODS:

Participants:

This study comprises 2 third year medical student cohorts: an experimental group (n=13) with an assigned disabilities curriculum, and a control group (n=20) without an assigned disabilities curriculum. Both cohorts are students at clinical campuses of Via College of Osteopathic Medicine-Carolinas campus in Spartanburg, SC. The study group denoted as “AnMed” includes 4 male students and 9 female students with an average age of 25.3, all of whom performed their clinicals at AnMed Health Medical Center in Anderson, SC. The control group denoted as “Spartanburg Regional” includes 12 male students and 8 female students with an average age of 26.3, all of whom performed their clinicals at Spartanburg Regional Medical Center in Spartanburg, SC.

Curriculum:

At the beginning of the year, each student at AnMed was assigned a YSHCN patient enrolled in the Transition Project (below). The students participated in a home visit (below). A lecture, “Medical Care of the Disabled Patient”, was presented to the AnMed students. This lecture is found in the STFM Residency Resource Curriculum.⁸ On another day the students viewed the video “Patient Voices”, a series of interviews and vignettes featuring real patients with disabilities encountering the health care system.⁹

Home Visit:

We partnered with a local organization, Family Connection of South Carolina, which provides support to families of people with disabilities. Their Physician Education Awareness Program helps providers grow in awareness of disabilities. Their representative conducted a group visit for our students to the home of a young person with disabilities.

Transition Project:

The YSHCN patients were all young people with either an intellectual or a physical disability who were between the

ages of 18-21 at the time and therefore transitioning out of the pediatric clinic to the family medicine clinic. We paired each AnMed student with a YSHCN patient. The medical student attended the patient's last visit at the children's clinic where the patient had been receiving longitudinal health care. The medical student assisted with compiling a medical summary as well as a validated “Readiness Checklist” developed by Gottransition.org, a project of HRSA.¹⁰ This checklist is a reminder for the patient and family to prepare for independent living. The student and patient/family chose one competency to develop over the course of the year with plans to revisit the checklist later. The medical student stayed in touch with the patient and family and organized the first visit at the family medicine clinic where the students have their family medicine experience. At that visit, the student was present and assisted the new provider in reviewing the medical history and the Readiness Checklist.

Measures:

Both groups were given the attitudes survey at the beginning of the academic year. The experimental group completed the assigned disabilities curriculum throughout the academic year. At the end of the academic year, both groups completed the attitudes survey again. The validated survey used in this study measures comfort levels treating and working alongside people with disabilities, negative impressions of self-perceptions of people with disabilities, and “conditional comfort” with patients with disabilities. This latter component refers to the difference in a common ambulatory office visit with a typical patient versus a patient with a disability.¹¹

Data Analysis:

The responses on the Medical Student Attitudes towards Persons with Disabilities surveys were analyzed by 2 different methods. Although both methods focused on examining the difference between end of year (EOY) and beginning of year (BOY) responses between AnMed and the control group, the first method looked at each question individually and the second method grouped the questions into one of 5 categories described by Symons, the author of the survey¹¹. Under both methods, survey responses were translated into a numerical value between 1 and 4. A response of “strongly disagree” received a value of 1, “disagree” a value of 2, “agree” a value of 3, and “strongly agree” a value of 4. Six questions on the survey were reverse-scored because a response of “strongly agree” correlated with a more negative attitude towards people with disabilities. The method described above was used to record the responses to all questions, except questions 1 and 2 which required a yes/no response.

RESULTS:

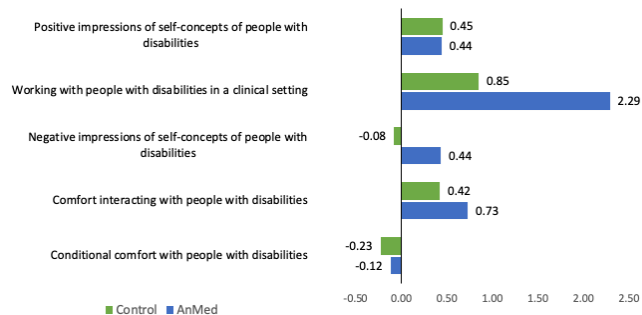
To analyze the effect of a disabilities curriculum on medical students, the responses between the 2 groups from the

beginning of the year to the end of the year are compared. We find it most helpful to group the survey statements into the 5 categories mentioned above. We show the comparisons in the graph below by category (Graph 1).

First, “positive impressions of self-concepts of people with disabilities” is measured by survey statements 5, 13, and 17. “Negative impressions of self-concepts of people with disabilities” is measured by survey statements 3, 8, and 11. These 2 groups of statements describe assumptions of attitudes of people with disabilities. The statements gauge how a medical student imagines the way a person with a disability sees himself or herself. For example, when the medical student imagines herself in the shoes of a person with disabilities, does she resent people without disabilities? These types of assumptions are prevalent among the medical community in general.¹² The AnMed students show a greater improvement in removing these types of stereotypes.

Next, “working with people with disabilities in a clinical setting” is measured by survey statements 21-19. This group of statements refers to the comfort level in treating people with disabilities. These statements compare a typical office encounter with 2 patients—one with a disability and one without. Many learners who encounter such a patient will get distracted or sidetracked by the disability. The improvement in the AnMed students in this group of statements is statistically significant ($p=0.016$).

The next group of statements, “comfort interacting with people with disabilities,” is measured by survey statements 4, 6, 7, 9, 12, 14, 18, and 19. These statements assess students’ comfort interacting with persons with disability not only in the healthcare setting, but also in daily life. The AnMed students demonstrate greater improvement in this category. The last group of statements, “conditional comfort with people with disabilities,” is measured by survey questions 10 and 15. While these statements show negative results for both cohorts, they are ambiguous. Both groups tended to disagree with question 10, meaning that if the patient were not “well-behaved” it would not bother them. For the others who agreed, perhaps their answer shows bias towards persons with disability. However, it would be natural to be uneasy around any misbehaving adult patient! Both groups tended to agree with statement 15, that they would be more comfortable if a person with a disability were accompanied by an aide. From the students’ perspective, in some situations it may be advisable to have an aide present.



Graph 1: Improvement of scores at AnMed Health and Spartanburg Regional on the *Medical Student Attitudes towards Persons with Disabilities Survey* by question category.

DISCUSSION:

Our clinical campus is located in Anderson, a community which has less benefits available for the disability community than in Charleston, where our main campus is located. Years ago, it came to our attention that in our area, people with disabilities in general, and YSHCN patients in particular, were being lost to follow-up and using episodic care as opposed to longitudinal care for their health needs. The medical staff was educated about these gaps in health care first. When medical students began coming here for their clinical education it seemed only natural to educate them to take care of people with disabilities.

Our curriculum is weighted toward actual encounters with persons with disabilities. We rely less on didactic sessions. There are several reasons for this approach. First, caregiver comfort with patients with disabilities has more to do with general knowledge of disabilities than with knowledge of specific disabilities.¹³ That general knowledge is assessed in the survey used in this project. Second, we believe comfort and knowledge of disabilities is more likely caught than taught. The patients themselves are often better at teaching the learner who wants to learn. Furthermore, the learner is more likely to be interested in disabilities when he/she forms a friendly relationship with an actual person. Finally, the amount of knowledge to become an expert on all disabilities is out of the range of most primary care providers; information pertinent to specific conditions is readily available at the time of contact, and that is a skill worth learning. We want the learners to understand that a receptivity toward persons with disability, not comprehensive knowledge, is the requisite to caring for them.

The challenges with the curriculum all arose from the transition project. As in the past, we experienced great difficulty contacting and scheduling the patients; this is one of the reasons for constructing this project in the beginning. In the future we will set up the follow-up visit at the time of the initial visit in order to give the med student and the patient/family a follow-up date. We will also obtain alternate phone numbers for contacting the patients/families. The med

students tended to lack confidence in contacting and following the patients, not taking ownership as much as we had hoped; in the future we will tie a grade to the project to motivate the students. The patients themselves made poor choices at times, thus sabotaging their health care. To address that, we would like to incorporate a group visit which might help them process their desires and goals.

There are several survey statements which show either similar results in both groups, or negative results in the AnMed group. Some of these are in the survey category “conditional comfort with people with disabilities”. Again, these statements are ambiguous and can be interpreted in different ways, as discussed above. Alternatively, the answers suggest that as the students gained more awareness of the complexity of patients with disabilities, they appreciated extra help with the patient visits. These answers are not inconsistent with greater comfort with persons with disabilities.

Another explanation might be rooted in a difference between the 2 groups which has not been mentioned: the control group reports more “structured experiences working with people with disabilities” (55% as compared with 38%). Perhaps more experience may have given the control group less of a perceived need for help from a caregiver.

Our data show strong benefits of a disabilities curriculum for medical students. Our results are convincing in the areas of “working with patients in a clinical setting”, “comfort interacting with people with disabilities”, and “positive impressions of self-concept of people with disabilities.” We believe improvement in this group of statements is due to exposure to persons with disability. Therefore, we suggest that the AnMed students improved in this category due to their experience with the curriculum.

We anticipate that our students will be more accepting, empathetic, and confident treating persons with disabilities not only in the community, but in the office setting. We also expect our students to be able to form differential diagnoses in the office with persons with disabilities that are similar to persons without, with the addition of conditions related to disabilities. That will make them excellent primary care physicians for persons with disabilities.

The AnMed teaching site is dedicated to training primary care physicians. Patients with disabilities represent a vulnerable population in primary care. At the same time, medical schools often do not train students to deal with patients with disabilities. On the contrary, negative attitudes towards patients with disabilities are common in the healthcare setting among students and staff. One of our goals was to counter these assumptions and remove prejudices toward the daily facts of living with a disability. We succeeded in both of these goals. In this way we hope to train physicians who treat patients with disabilities without bias.

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Appendix A: Medical Student Attitudes Toward Persons with Disabilities

Demographics: Age: _____ Gender: _____

I. Please circle the correct response.

- Have you had any structured experiences working with people with disabilities (i.e., volunteering at a group home, teaching) aside from medical school?
 - YES NO
- Do you have a friend or relative with a disability who you see at least occasionally?
 - YES NO

II. Please circle the appropriate number which best corresponds with how you feel about the statement. Choose only ONE response for each question.

	Strongly Disagree	Disagree	Agree	Strongly Agree
3. Most people with disabilities feel sorry for themselves.	1	2	3	4
4. I am comfortable being around a person who has an intellectual disability (i.e. mental retardation, autism).	1	2	3	4
5. People with disabilities are as happy as people without disabilities.	1	2	3	4
6. I would be comfortable interacting with a person with an intellectual disability who was in the community on his or her own (i.e., without staff members or caretakers).	1	2	3	4
7. I would be comfortable being around a person who uses a wheelchair.	1	2	3	4
8. Most people with disabilities resent people without disabilities.	1	2	3	4
9. I would be comfortable being around a person who is deaf.	1	2	3	4
10. I am only comfortable around people with intellectual disabilities if they are well-behaved.	1	2	3	4
11. Most people with disabilities expect special treatment.	1	2	3	4
12. I would be comfortable working with a person with an intellectual disability who had someone assigned to supervise and train her.	1	2	3	4
13. Most people with disabilities are not ashamed of their disability.	1	2	3	4
14. If I were visited by a person who is blind, I would be comfortable helping him or her navigate the environment.	1	2	3	4
15. I am more comfortable around people with intellectual disabilities when they have someone who is not disabled to help them.	1	2	3	4
16. If I introduced a person with disabilities to my friends, I think they would feel uneasy.	1	2	3	4
17. People with disabilities should be cared for in any primary care office as opposed to a specialty clinic.	1	2	3	4
18. I would feel comfortable living next door to a person with an intellectual disability that lives by himself.	1	2	3	4
19. I would be comfortable living in a neighborhood where there is a group home for people with various developmental disabilities (e.g., Down Syndrome, Cerebral Palsy, Mental Retardation, etc.).	1	2	3	4
20. I would feel comfortable being around a person with an intellectual disability in public even though his behavior might be a bit bizarre (e.g., rocking back and forth, talking loud, etc.).	1	2	3	4

III. Please review the following 2 scenarios (A and B) and answer the questions regarding the scenarios. Please circle the appropriate number which best corresponds with how you feel about the statement.

Scenario A:

You enter the exam room. A middle-aged man and woman are there. He tells you he is experiencing chronic abdominal pain.

	Strongly Disagree	Disagree	Agree	Strongly Agree
21. I have had experiences similar to scenario A.	1	2	3	4
22. In scenario A, I would be comfortable determining the role of the man vs. the woman in providing the history of the complaint.	1	2	3	4
23. In scenario A, I would be comfortable performing a physical exam on the patient.	1	2	3	4
24. In scenario A, I would be comfortable establishing a differential diagnosis for the abdominal pain.	1	2	3	4

Scenario B:

You enter the exam room. A middle-aged man is seated in a wheelchair. Standing behind him is a woman of about the same age. The patient in the wheelchair appears to have spasticity in all 4 limbs. He greets you by saying "hello". His speech is somewhat garbled, though intelligible. The woman tells you that the patient is here because he is experiencing chronic abdominal pain.

	Strongly Disagree	Disagree	Agree	Strongly Agree
25. I have had experiences similar to scenario B.	1	2	3	4
26. In scenario B, I would be comfortable determining the role of the man vs. the woman in providing the history of the complaint.	1	2	3	4
27. In scenario B, I would be comfortable performing a physical exam on the patient.	1	2	3	4
28. In scenario B, I would be comfortable establishing a differential diagnosis for the abdominal pain.	1	2	3	4

29. Consider scenarios A and B. Are there elements in either scenario which would make you uncomfortable in the clinical encounter? If so, please describe briefly.

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