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Independent Study Projects

Title

Improving Medical Students' Understanding of Patients with Cognitive Disabilities Through Service Learning.

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***Improving Medical Students' Understanding of Patients with Cognitive Disabilities
Through Service Learning***

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Rationale for project: Medical education regarding how to communicate with individuals with cognitive disabilities (IWCD) is not part of the curriculum of most U.S. medical schools. These patients experience significant barriers to healthcare. A volunteer service event may familiarize students with this patient population and their unique healthcare needs. This project aims to answer two main research questions:

- What do IWCD and their families need from their medical care?
- How can medical students be educated to address those needs without a formal curriculum?

Description of project objectives and how they were met:

Project Objective	How it was met
To assess whether UCSD medical students think curriculum on IWCD is useful to their training as future doctors	Student Needs-Assessment Survey of 100 UCSD MSIs and MSIIIs
To assess healthcare barriers faced by IWCD by surveying their family members	Survey of 28 family members of SOSC athletes
To train students on how to interact respectfully with IWCD in the context of a Special Olympics of Southern California (SOSC) sports event	4 SOSC events held and 11 students participated
To bring medical students to Special Olympics events to give them exposure to IWCD and the healthcare barriers they face	4 SOSC events held and 11 students participated
To evaluate qualitatively and quantitatively whether students found the above events beneficial in their learning about IWCD in lieu of a curricular intervention	11 students filled out surveys before and after the SOSC events

Project Methods:

A needs-assessment survey was conducted of 100 medical students. The survey showed the following:

- 58 students answered that they did feel comfortable speaking and listening to IWCD, but these results are skewed positively because 29 of those students had longitudinal experience working with an IWCD before taking the survey ("My brother has autism" or "I tutored a cognitively delayed student in high school", etc). 33 students answered they neither agree nor disagree that they feel comfortable speaking and listening to IWCD. 9 students said they did not feel comfortable.
- 11 students answered that they did have a good understanding of healthcare barriers faced by IWCD, while 53 said they did not have a good understanding of these barriers and 36 neither agreed nor disagreed.
- 28 answered that they understood the needs of families of IWCD, but these results are skewed positively because 18 of those students had longitudinal experience with IWCD before taking the survey. 48 students answered that they did not have a good understanding of the needs of an IWCD's family. 24 students neither agreed nor disagreed.

97 out of 100 students answered that they would like to learn more about their future IWCD patients through formal curriculum (the options given on the survey was to circle any of the following that they wanted: a 2-unit elective course, POM lectures, POM practical sessions like discussions or GOSCEs, or None of the above). **17 students chose a 2-unit elective course, 74 students chose POM lectures, and 62 students chose POM practical sessions such as discussions or GOSCEs.** One student suggested a lunch talk by writing it on the survey, as lunch talks was not one of the answers provided to circle on the survey. Three students chose “None of the above and here’s why” with a write-in space following. Their comments were “above suggestions are too time-consuming”, “very specialized → elective if you want it”, and “honestly I think there are more relevant, commonly encountered issues which I’d rather learn about.”

Under IRB-approval, 11 students attended a Special Olympics sports practice which included direct interaction with athletes and the families of the athletes. 2-5 students attended each event, and a total of 4 events were held (at practices for bowling, tennis, floor hockey, and softball). Before each event, I (Kavya Rao) gave them a quick talk on Special Olympics volunteer guidelines. This talk included tips such as: treat the athletes as if they were cognitively able and then adjust speaking style to the needs they display, allow the athletes dignity and respect by speaking to them at eye level and slowing down speech if they prefer that.

Students interacted with athletes by talking to them and playing sports. They were encouraged to ask the athletes informal questions, such as whether they enjoyed being on the team and what they liked about playing the sport, in an effort to get to know them. The students interacted with the athletes in different levels appropriate to the athletes’ ability level and under supervision of the coaches. For example, some students would hit tennis balls across the net for an athlete to return; some students would cheer on the athletes at the bowling lanes and floor hockey court; the students at the softball practice participated in a scrimmage with the athletes. Students learned varying communication styles, because some athletes were nonverbal and responded best with smiles, cheering, high-fives, and demonstrating how to do a particular skill (such as swinging a softball bat). Other athletes were verbal and talked with the students but in a pathologic way (e.g. overly friendly to strangers, facial motor control issues with speech). Students also learned the athletes’ physical capabilities while watching them play, and emotional capabilities while observing the team camaraderie (e.g. the athletes are extremely supportive of one another).

Students also talked to family members of the athletes during these sessions. The family members were consented to speak to students and fill out a survey describing what barriers to care their athletes faced in the healthcare system. 28 family members participated over the 4 sessions. These family members were asked to speak about their experience bringing their athlete to doctors over the years, and the athletes could contribute to the discussion if they so chose. The family members were encouraged to tell only what they wanted to tell and stop whenever they wanted to stop, and they were told that no personal healthcare data need be disclosed but rather that the goal was to teach students how to be better doctors towards people like their athletes.

The 11 students were surveyed before and after the event about 1) their knowledge of healthcare barriers faced by IWCD, and 2) their comfort level in working with IWCD. No students voluntarily withdrew from the study.

Under IRB-approval, 28 family members of IWCD were surveyed on their experiences with the healthcare system. No family members voluntarily withdrew from the study. Overall, no parents or students were eliminated from the study.

Attachments:

1. Student survey (the same document was used as the Needs-Assessment survey and as the IRB-approved student survey)
2. Student consent document
3. Family survey
4. Family consent document
5. Human Research Protections Program approval note

Project Achievements:

11 students to date have participated in a Special Olympics volunteer event as part of the study. After completing the event, 10 students reported improved knowledge of healthcare barriers faced by IWCD and improved knowledge of needs of family members of IWCD. 8 students reported improved ability to demonstrate respect to IWCD. 5 students reported improved comfort level in interacting with IWCD. 9 students reported an increased likelihood that they would ask friends and colleagues not to use the word “retarded” as a negative descriptor (I consider this an important measure of how willing medical students are to advocate for this population in daily life). Students provided qualitative written and verbal feedback that demonstrated that they felt inspired and moved by the events. All students surveyed would like formal teaching in this subject, implying that they think this population will be a small but historically underserved portion of their patient population no matter what residencies they choose to pursue.

Examples of qualitative feedback from student participants (anonymized):

- *“I was a little hesitant going into this experience due simply to my inexperience, but just a few seconds in I felt so moved and so comfortable. **This has definitely inspired me to do more research and look into the questions I have regarding healthcare for patients with disabilities. From today I’ve realized the power of testimony from families of the athletes and how much I can learn by getting involved with the patient populations directly.**”*
- *“Really enjoyed being able to interact with not only parents and family but also with the athletes. The diversity of humanity is so beautiful.”*
- *“This was a fantastic event. **It was wonderful how willing parents and athletes were to speak to us.** I learned a lot and will take this experience with me in bettering my life and the lives of my patients.”*
- *“I really enjoyed the experience and stepping out of my comfort zone. **Seeing what the athletes were capable of** and talking to the parents really raised my awareness and comfort levels with this unique population!”*

I believe this project is an example of changing the perception of a negatively stereotyped and historically underserved patient population from the ground up, starting with these 11 students who may go on to have less “sheltering” and more “empowering” attitudes towards these patients in the future, and then teach the same outlook to the medical students they train.

Of the 28 parents of IWCD surveyed, 15 reported that their doctor did not routinely set realistic, achievable goals for their child’s learning. 13 reported their doctor did not routinely let them know what to expect with each stage of their child’s development. 17 indicated that their doctor did not routinely work well with other members of their child’s care team (e.g., speech therapist, teacher). 9 respondents felt their doctors did not consistently explain treatment options so that they could understand them. All respondents had qualitative comments to me and to the students that indicated they felt grateful simply to be listened to by medical professionals regarding their concerns. Many qualitative comments indicated

that they were relieved by diagnosis but that how doctors chose to deliver the diagnosis was important to the emotional outcome of the family. Families often advised students to focus on what their athletes' capabilities were rather than continually reiterating to families that their athletes had limitations to a "normal" life.

Partnering community organizations with volunteer service events can educate students on barriers to care for underserved patient populations. Such partnerships can provide students with benefits for future practice such as increased comfort level in speaking to IWCD with varying communication needs.

Future:

To try to spread this concept of service-learning to other medical schools and to obtain feedback on our project, Dr. Yi Hui Liu and I have submitted this project as an abstract/poster presentation to a medical education conference, and plan to submit the abstract to a family-centered care conference as well. I hope that the connections we have made will encourage other UCSD students to continue the alliance made between UCSD and Special Olympics of Southern California. I also think the success of the service learning project with these 11 students, and the fact that close to 100 preclinical students at our school would appreciate curriculum addressing this population's needs (through lecture, didactic, GOSCE, PBL tie-ins, etc), demonstrates that a curricular intervention would be received well, should administration choose to pursue it.