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# Experiences of disabled students in undergraduate medical education

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#### ABSTRACT

**Purpose:** Since people with disabilities (PwD) are underrepresented in medical education, the authors of this article conducted a qualitative research in the form of an in-depth interview with students with disabilities from a medical school in Brazil, to characterize their experiences in medical education and identify barriers and facilitators to inclusion.

**Materials and Methods:** Participants were recruited by snowball sampling, signed an informed consent form, and completed a socioeconomic questionnaire. They were interviewed individually with open-ended questions so that they could develop narratives.

**Results:** The students identified some barriers to inclusion - teachers' lack of knowledge about students' special needs, students' own lack of knowledge about their needs during the medical course, underestimation of the disability by teachers and classmates, difficult access to college buildings - and facilitators, such as acceptance of the disability by professors and colleagues, proactivity of professors and colleagues in adapting practical learning scenarios.

**Conclusion:** Students identified peer and teacher acceptance as an important determinant of inclusion, which is in line with the biopsychosocial view of disability. They also reported doubts about their ability to practice medicine, which dialogues with literature research that points to a medical culture that expects nothing less than perfection from students.

**KEYWORDS** 

Undergraduate medical education; disabled persons; inclusive education; qualitative research

# Introduction

The inclusion of people with physical, visual and/or hearing disabilities in undergraduate Medical education is, at the same time, a controversial issue and yet one that is little discussed. In the United States, the Americans with Disabilities Act (ADA) of 1990 mandates that all educational institutions provide reasonable accommodations for people with disabilities (PwD) (Eickmeyer et al. 2012). However, in spite of this theoretical legal protection, studies show that, in practice, PwD are still struggling to be included in Medicine. A prevalence study conducted in 87 American medical schools in 2019 (Meeks et al. 2019) pointed to a percentage of 4.6% of students with disabilities, which represented an increase of 69% when compared to 2016. Despite the considerable growth in the presence of PwD, the percentage of students with disabilities in undergraduate medicine is still low when compared to the percentage of PwD in the overall population, which is about 26% in the United States, according to the Center for Disease Control (Centers for Disease Control and Prevention 2018).

This points to the existence of factors that hinder inclusion, which include inaccessible physical structures, discrimination from admissions committees, and a belief in medical culture that students must be 'undifferentiated', therefore able to opt for any specialty at the end of the medical course, and physically 'perfect' (Mercer et al. 2003). This belief makes any conversation centered around

# **Practice Points**

- Some barriers prevent the full inclusion of PwD in Medicine: lack of prior knowledge of faculty about the students' conditions, underestimation of disability, lack of addressing disability in the curriculum.
- The degree of acceptance of disability by classmates and professors is a key point for the inclusion of PwD in Medicine.
- The idealized view of the medical student by the medical community can hinder inclusion.
- Some actions can promote the inclusion of PwD in medicine: establishment of groups of disabled students who advocate for their rights; individual assessment of medical students with a group of professors trained in inclusive education to determine their special needs; available information on accessibility for disabled students on the website of each institution, in order to inform future students of the possibility of making accommodations.

inclusion of PwD a hot-button issue. Another hindrance to inclusive education is the lack of visibility of PwD. A study conducted in 75 American medical schools (DeLisa and Thomas 2005) showed that 36 of them (48%) did not address the issue of disability in their curriculum, even

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though some reported that they had previously admitted disabled students.

In addition, access to education does not concern only the entry of disabled students in higher education, but also their permanence in this space, as well as the effectiveness of the education they receive, which must be adapted to their special needs. This belief is in line with the biopsychosocial view of disability, which states that disability results from the articulation between organic or structural dysfunction of the body and the limitation to perform and participate in social activities, plus environmental factors that impose facilitators or barriers to social participation (Cieza et al. 2018).

To identify the facilitators and barriers that determine the experience of medical students with disabilities and to propose possible inclusive institutional attitudes and policies, the authors of the present study interviewed students with disabilities from a traditional Brazilian medical school. We carefully analyzed the interviews, seeking to better understand this population.

# **Materials and methods**

We conducted an exploratory qualitative research with disabled medical students from a traditional medical school in Brazil. The inclusion criteria for research participants were: students enrolled in any stage of the undergraduate medical course in the affiliate institution as of 2020, who have physical, visual and/or hearing disabilities. The exclusion criteria were: medical students with physical, visual and/or hearing disabilities from other institutions, students with mental, learning and/or developmental disabilities.

For the selection of participants, we used the snowball sampling technique, a form of non-probability sampling that uses reference chains (Heckathorn 2011). We made contact with some interviewees, who referred more students who fit the profile, and so on. We chose this technique for the current research due to the restricted number of disabled students in the aforementioned institution and course.

The participants answered a socioeconomic questionnaire that allowed them to be divided into groups, according to the Social Reproduction Index (SRI). Group I is the group with greater socioeconomic stability, while groups II, III, and IV face greater precariousness (Trapé 2011).

After that, we conducted an individual in-depth interview with each participant, in which they were able to talk freely about their experiences in Medical education. To identify the meanings that the interviewees attributed to their experiences, we used open questions, present in a guiding script. Depending on the narrative developed by the participant, new questions were spontaneously added, so that each student's experience was contemplated in the most global way possible. This type of interviewing has been long recommended for qualitative research (Britten 1995).

The interviews were conducted through the Google Meets platform. All interviews were recorded and transcribed in full for the purpose of data analysis. The analysis of the transcripts by 3 different researchers allowed the identification of recurring themes in the students' narratives.

All research ethics precepts present in the Declaration of Helsinki (1964) were followed in this investigation. All participants signed the Informed Consent Form. The project was approved by the affiliate institution's ethical committee.

## Results

Nine students participated in the study, designated here by the codenames S1 to S9. Two of the participants did not pass their first year of the undergraduate medical course (S4 and S6) due to insufficient grades. The application of the SRI identified two groups with distinct social conditions (GI and GII). Six of the interviewed students (66.6%) were classified in GI and 3 were classified in GII (33.4%). Therefore, the majority of the participants showed high socioeconomic scores, presenting stable working and living conditions. The socioeconomic profile of the participants can be found in Table 1.

The following themes were the main subject matters apprehended from the participants' narratives during their in-depth interviews.

#### Theme 1: Entry into medical education

University admission for PwD in the institution where the research was conducted can occur through the affirmative action system or through general competition. The affirmative action system seeks to cover possible inequalities in the trajectory of students, but in order for the disabled students to qualify, there are several different requirements that not all of them could meet:

I didn't get in through the disability quotas because they have other requirements that you have to fulfill, [such as] having studied in public school in high school. [S2]

When students enroll, they receive a written form in order to put in requests for possible adaptations that they will need during Medical school. However, the students have no knowledge of what the course is actually like, and therefore they don't know what their needs will be:

Table 1. Socioeconomic profile of the 9 disabled medical students that participated in the current research (2020).

Identification	Race/color	Type of high school education	Type of disability	Year in medical school	SRI
S1	mixed	public	physical	third	GI
S2	white	private	physical	third	GI
S3	white	public	physical	third	GI
S4	white	public	visual	second	GI
S5	white	public	physical	second	GI
S6	black	public	hearing	first	GI
S7	white	public	physical	third	GII
S8	mixed	public	physical	first	GII
S9	white	public	physical	first	GII

They give us a paper [asking what] you will need. Of my knowledge at the moment registration of what the medical course is, I thought ... I don't think I will need anything, which was not true. [S7]

Since most of the students with disabilities came from public schools, in addition to disability-related issues, some of them reported inclusion barriers related to academic difficulties:

I have quite a bit of difficulty, not only [due to] physical limitation, but also because of the issue of my lagging education, [...] especially close to my classmates, who studied in the best schools. [S9]

# Theme 2: Identity and socialization

Students reported that, in certain situations, their disability can be underestimated by classmates and teachers, which can bring negative repercussions:

I have heard several times [expressions] that hurt to hear: you don't have any trouble, you can walk, you can breathe, you can see. [...] when someone looks at your disability and says 'this is nothing' [...] they reduce it to zero importance, and you know that it [...] matters. [S1]

'I think the people [...] in the room didn't even know that I need to make some adaptations because I think they see me doing everything with everyone else [...] but I don't want to live as if the disability didn't exist.' [S2];

The teachers never treated my disability as an issue. [ $\dots$ ] they always tried to just exclude this part of my life, [and] I felt less included in relation to my classmates. [S7]

There were also some reports of unpleasant episodes in which disability was not underestimated, but highlighted in a negative light:

The teacher [...] explained how we needed to do the procedure. I hadn't put [my hand] exactly in the right place [...] and he said, jokingly, 'it looks like you have a crooked arm', and that's exactly it, I have a deviation of the radius. [S1]

Despite these difficulties, students reported, in general, a good acceptance by their classmates:

The university environment is very welcoming [...]. I always had friends that helped me. [S5]

I never imagined that my classmates would help me so much. [S4]

My current classmates [...] are welcoming. None of my colleagues have ever discriminated against me because I have a disability. [S7]

However, some also reported anguish related to the difficulty of participating in athletic games and competitions in their university life, because these activities are focused on physical abilities:

They train every day, and I can't do that. [S3]

I can't participate because of the physical impact, you have to run a lot. [  $\ldots$  ] I get a little sad, because I wanted to participate. [S9]

## **Theme 3: Teachers**

Most of the professors in the medical course are not aware of the students' special needs, especially at the beginning of undergraduate education: So far in my time in medical education I have never seen a teacher [...] with a list of people that he knows that have a disability and he tried to integrate these people or adapt the activities. [...] It was never a proactive effort of the teacher. [S3]

[...] in the beginning, they did not know the extent of my needs and the limitations that the disability itself imposes, but with time these limitations became explicit. [S5]

Throughout the coexistence with the disabled students, teachers come to know their special needs, and many try to help them by adapting certain lectures or activities:

I couldn't see what was on the test. [...]. When they realized it, they offered me tests with a bigger font, which helped me a lot. They also allowed me to take the exam in my notebook. One teacher sends me enlarged slide presentations before the classes. [S4]

In the practical scenarios [...] we had cardiopulmonary resuscitation and [...] I had to hold the ventilation device at the same time as I was holding the face mask, I couldn't do both at the same time, but the teachers next to me asked a colleague to help me and everything worked out fine. [S2]

I always had the help of the anatomy teacher. He took the [anatomic] body parts from the table at the lab and brought them closer to me so I could study. [S5]

#### Theme 4: Lectures

The long duration of the lectures in the medical course and the space in which they take place caused problems for some students:

The pain gets in the way during classes, [...] I can't stretch my legs [...]. The classes could be shorter, and the room could have more space. I have to get up to [...] move around. [S3]

The long way students have to walk in between lectures due to the different locations of the auditoriums also presents itself as a difficulty for students with disabilities:

[Due to the] campus being so large, we have to cross several streets [...] in order to change from class to class. There have been situations when the wheelchair was tipping over the sidewalk and I needed help to get up. [...]. The access to the buildings for me is through the parking lot, [which] many times is full of cars and I just couldn't get through it. [S5]

[...] moving around on campus wears us out and makes us tired due to our limitations. [S8]

For hearing impaired students, it is often difficult to hear the professor during the lectures:

The microphone [that teachers use during classes] is not very loud, it doesn't make much difference from talking without one. Not hearing makes it difficult for me to learn. In Medicine there are many new words that I don't know, so sometimes I don't understand. I am too embarrassed to ask the professor to repeat [...]. [S6]

This inequality could be solved with the use of amplification technologies, however these are of restricted access:

I have a device [...] that I can place near the professor and it connects directly to my hearing aid. [The university] didn't guarantee that I would get it because the government only provides it for people under 18 years old [...]. [S6]

# **Theme 5: Practical abilities**

The practical learning scenarios in which students need to learn practical medical skills can be worrisome situations for students with disabilities, because they demand physical effort. Many students reported that they put themselves at the last place in line, for fear of not being able to perform the activity:

 $[\ldots]$  It was a class on washing your hands before scrubbing into surgery, and I already [was] wanting to go to the back of the line. [S1];

We were having a lecture on intubation, and then we had to intubate the dummy to practice. I thought, if I can't do [the activity] in front of everybody, I'll be embarrassed. [Students] formed a line, and I waited for everyone else to do it first, so I could do it at the end. I was nervous. [S2]

When we were learning how to do cardiac massage, I didn't know how to position my hands, because I have an upper limb that is shorter than the other. I was feeling so embarrassed, [...] I positioned myself to be second to last in line. What if I get in front of my colleagues and I can't do it? [S7]

In these situations, students reported that they would feel less anxiety and embarrassment if they could talk to the teacher responsible for the activity before the class started. Peer support also facilitates the process:

I couldn't reach the teacher and explain to him that I had a disability, ask if he could help me [...] [S7]

I waited until it was just me and a friend [...] and I thought if I can't do it properly, it's okay, because she is my friend and she won't judge me. [S2]

[...] in the physical aspects where I had some difficulty, I always got some help from friends. [S5]

Visits to hospitals and/or outpatient clinics are also difficult moments for PwD with mobility impairment:

I have attended many clinics outside the University [...] which brings the problem of accessibility. Many times I confess that I was saddened when I left, because I really didn't see a perspective of inclusion. [S5]

In the surgical center, I sat in the anesthesiologist's chair. [...] this was bad because I didn't have a good view of the surgical field. [...] maybe if I could get a higher chair, I could see. [S3]

The medical visit at the patient's bedside and the case discussions with the professors in the corridors of the hospital can also bring barriers:

We were discussing a case [...] in the corridor, with everyone standing up. That doesn't work for me. [S3]

When we're at the patient's bedside, when the professor is explaining, he has to speak in a lower voice so he doesn't disturb the patient, or [...] sometimes when we're interviewing a patient, some of them speak very quietly [...] I end up not listening, and I don't ask people to keep repeating themselves [...] [S6]

The dissection of cadavers in the anatomy laboratory demanded adaptations for students with differences in the upper limbs:

When we started to practice dissection [...] there was the issue of the glove, because my right hand is smaller and it has 2 fingers, so the normal glove does not fit well. [...] my

mother and I found a factory that produced custom gloves for us. [S2]

Other difficulties emerged in the student's contact with the patient, especially at the time of the physical examination:

My biggest difficulty is  $[\,\ldots\,]$  the contact with the patient  $[\,\ldots\,]$  [S6]

[...] in the physical examination, [...] I think there are some procedures that I won't be able to do. When I become a doctor [...] I hope I will be able to examine my patients in a complete way, adapt it as much as possible to my limitations. [S7]

#### Discussion

The narratives of medical students with disabilities are a rich source of information about how the insertion of this population in the medical and academic environment occurs. In this study, we identified some barriers to the full inclusion of these students: lack of prior knowledge of the faculty about the students' conditions, lack of dialogue between students and teachers about possibilities of adaptation, underestimation of disability, lack of approach to disability in the curriculum (showing the inflexibility of medical education), lack of accessible structure in lecture halls and auditoriums. Moreover, the students' reports corroborate the biopsychosocial view of the disabled individual, since they identify social and cultural attitudes towards disability as strong determinants of inclusion.

In this sense, the degree of acceptance of disability by classmates is identified as a key point for the insertion of the student in the institution of higher education. When disability is seen naturally, the person with disability fits more easily into the student body, because his or her presence is validated by the social context. This synthesis of the experiences of the interviewed students is in agreement with the reflections of specialists in medical education. A survey by the American Association of Medical Colleges (Meeks et al. 2018) identified the presence of a peer support network as one of the most crucial determinants in the development of accessible universities for PwD.

The international literature goes even further, stating that the view of the medical community as a whole can hinder inclusion. Stergiopoulos et al. (2018) states that there is a culture in medicine that sees the doctor as a perfect person. This discourages any student from demonstrating weakness and asking for help, and thus students with disabilities are afraid to demonstrate their special needs. According to DeLisa and Thomas (2005), such expectation of perfection causes PwD to be seen as less capable of practicing medicine. In our work, it can be observed that many students asked themselves if they were capable of attending medical school, and this lack of sense of belonging manifested itself in a severe discomfort in some situations. Therefore, some students did not ask teachers for help and tried to hide their disability from peers by going to the back of the line in practical activities.

In addition to the barriers to inclusion that arise from the medical community, it is important to consider the barriers that arise from the economic division of society in general. Disabled students coming from more vulnerable economic backgrounds suffer a double exclusion, both for their disability and for their social origin, and therefore they reported more difficulty in entering University and in their academic progression.

All these reflections point to the need for something beyond the already existent inclusion laws: the construction of a medical community committed to accessibility. This can start from the understanding that medical students with disabilities have personal experiences that can help them develop empathy throughout their profession - a skill that is currently in high demand. Woolf et al. (2007) state that students with personal illness experiences were perceived by trained teachers as more mature and compassionate. However, the study pointed out that these students also showed high levels of anxiety associated with not meeting expectations, which speaks directly to the results obtained in our research. Thus, the need for dual work on disabled medical students comes into question: exploring how deeply their experiences can help them in understanding the patients, but also working on the community's respect for the limitations that each individual has.

The analysis of the interviews with the students with disabilities also raises concrete possibilities for intervention that can advance the development of inclusive education, such as: establishing representative institutions led by disabled student groups that would encourage the University administration to invest in accessible spaces (ramps, elevators) and special technologies (microphones and amplifiers for professors, digitized tests for visually impaired students); assessment of each medical freshman by a group of teachers instructed in inclusive education to determine what special needs may arise throughout their time in Medical school; easily available information on accessibility on each institution's website to inform future disabled students on the possibility of making accommodations; conducting more surveys with disabled medical students to increase the medical community's knowledge regarding the needs of this population; establishing a curriculum for all medical students (abled bodied and otherwise) to learn about disabilities in their peers and patients, therefore raising awareness on this topic and increasing the quality of care for disabled patients. With initiatives like these, it will be possible to start the path towards an inclusion that goes beyond the theory of the law and manifests itself in practice.

#### **Disclosure statement**

The authors report no conflicts of interest. Two of the authors of the article were also included as participants in the project, therefore they were interviewed on their experiences as PwD in the position of Medical students.

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This project received no source of funding or material support from any organization.

# **Ethical approval**

The project was approved by the affiliate institution's ethical committee (COEP-UNIFESP), approval document number 4.286.552.

# **Geolocation information**

This study was conducted in Sao Paulo, SP, Brazil.

#### Glossary

**Undifferentiated graduate**: A medical student which theoretically could follow any specialty in the future, specifically used to say that students with disabilities are not undifferentiated because they could not follow surgical specialties.

**Biopsychosocial model**: A model which views disease as the result of organic disfunction paired with societal and environmental factors.

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