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Developmental Disabilities in Undergraduate Medical Education: The University of Toronto Experience

Les troubles du développement dans l'enseignement médical de premier cycle : l'expérience de l'Université de Toronto

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Abstract

Background: *Although people with intellectual and developmental disabilities (IDD) are expected to access mainstream healthcare, doctors are ill-prepared to care for this population. Given the currently limited exposure to IDD in the medical curriculum and the healthcare challenges faced by the IDD population, the following study had two main objectives:* **(1)** *Assess preclinical students' knowledge of IDD and attitudes toward IDD; and* **(2)** *Explore the experiences, learning outcomes, and attitudinal changes of medical students participating in a student led seminar series on IDD at the University of Toronto.*

Methods: *The project consisted of two components: a needs assessment survey and focus groups. The survey explored 36 preclinical (Years 1-2) students' prior experience with IDD, knowledge and attitudes toward IDD, and educational needs in this area. The second component of the study involved focus groups with 10 students who took part in a six-week "Developmental Disabilities Seminar Series."*

Results: *Survey respondents reported a wide range of previous experience, good knowledge and open attitudes toward people with IDD. Thematic analysis of the focus groups revealed three main themes: (1)*

The universality of person-centred communication skills; (2) The value of first-hand exposure to people with IDD; and (3) Appreciation for available community resources.

Conclusion: *This project helped identify some of the educational needs of first- and second-year medical students in the area of IDD and could guide future curricular efforts to better serve this population.*

Résumé

Contexte : *Bien que les personnes ayant une déficience intellectuelle et développementale (DID) soient susceptibles d'avoir recours aux soins de santé courants, les médecins sont mal préparés pour soigner cette population. Compte tenu d'un contact actuellement limité avec la DID dans le curriculum médical et des défis de santé auxquels est confrontée la population ayant une DID, cette étude avait deux objectifs principaux : (1) évaluer les connaissances pré-cliniques et les attitudes des étudiants au sujet de la DID et (2) explorer les expériences, les résultats d'apprentissage et les changements d'attitude des étudiants en médecine participant à une série de séminaires sur la DID dirigés par des étudiants à l'Université de Toronto.*

Méthodologie : *Le projet comprenait deux volets : un sondage d'évaluation des besoins et des groupes de discussion. Le sondage a exploré l'expérience antérieure, les connaissances et les attitudes de 36 étudiants de niveau pré-clinique (années 1 et 2) en lien avec la DID ainsi que leurs besoins éducatifs dans ce domaine. Dix étudiants ayant participé à une série de séminaires de six semaines sur les troubles du développement ont pris part aux groupes de discussion.*

Résultats : *Les répondants du sondage rapportent un large éventail d'expériences antérieures, de bonnes connaissances et des attitudes d'ouverture envers les personnes ayant une DID. Une analyse thématique a révélé trois thèmes principaux au sein des groupes de discussion: (1) l'universalité des habiletés de communication centrées sur la personne, (2) la valeur d'un contact direct auprès des personnes ayant une DID et (3) l'appréciation de la disponibilité des ressources communautaires.*

Conclusion : *Ce projet a aidé à identifier certains des besoins éducatifs chez les étudiants en médecine de première et de deuxième année dans le domaine de la DID. Il pourrait guider les efforts futurs du programme pour mieux servir cette population.*

Introduction

People with intellectual and developmental disabilities (IDD) comprise approximately 1-3% of the general population (Sullivan et al., 2011) however estimates vary widely (Friedman, Gibson Parrish, & Fox, 2018).. Historically, people with IDD lived in institutions, where specialized physicians managed their healthcare. This is no longer the case in many parts of the developed world, where people with IDD are an increasingly integrated demographic, often living in independent or semi-independent accommodations (Brown & Radford, 2015; Davis, Fox-Grage, & Gheshan, 2000;). As a result, their health care and management have shifted to the domains of family medicine, psychiatry, and community-based services. In parallel with the deinstitutionalization movement, there has also been a perspective shift away from the medical model with regards to IDD, with a greater emphasis on community inclusion (Iezzoni & Long-Bellil, 2012).

Despite these promising changes, individuals with IDD continue to face higher levels of poverty and unemployment, live in subpar housing conditions, and experience alarming levels of health disparities in physical and mental health (Kendall & Owen, 2015). Additionally, people with IDD have ongoing unmet health needs, often with inadequate focus on health promotion and poor access to holistic, high-quality health care services (Krahn, Hammond, & Turner, 2006). Consequently, adults with IDD are more likely to visit emergency departments and be hospitalized repeatedly, remain in hospital after being ready for discharge and die prematurely compared to the general population (Lin et al., 2019).

In order to better serve people with IDD and their families, there has been growing recognition of the need for better training of current and future healthcare providers. Several recent Canadian studies have found that educational initiatives focused on IDD have resulted in improved knowledge, skill and comfort levels surrounding IDD for participants in these initiatives, including primary-care providers (Balogh et al., 2015) and students from a variety of health disciplines such as medicine, nursing, psychiatry, and rehabilitation (Jones, McQueen, Lowe, Minnes, & Rischke 2015). Finally, a study by Coret, Boyd, Hobbs, Zazulak and McConnell (2018) demonstrated the value of experiential and reflective learning in the context of communication skill development between medical students and ‘patient educators’ with IDD. All these studies underline the need to educate future healthcare professionals about IDD early on in their training in order to bring about long-term changes in attitudes and practice styles towards patients with IDD.

Within the context of undergraduate medical education (UME) at the University of Toronto, preclinical students (years 1-2) can opt to take an elective after-hours seminar series. The “Developmental Disabilities Seminar Series” (DDSS) involves six interactive sessions aimed to equip medical students with the skills, tools, and resources to be able to appropriately communicate with people with IDD and their families via experiential learning. This student-led seminar series was created with the recognition of the rather limited IDD-specific teaching provided in medical schools.

Given the currently limited exposure to IDD in the medical curriculum and the healthcare challenges faced by the IDD population, the following study had two main objectives: (1) Assess preclinical students’ knowledge of IDD and attitudes toward IDD; and (2) Explore the experiences, learning outcomes, and attitudinal changes of medical students participating in the seminar series

Materials and Methods

Participants

The study took place at the Mississauga Academy of Medicine (MAM), a satellite campus of the undergraduate MD program at the University of Toronto (Ontario, Canada) with 110 first and second-year students. The focus on students in years 1 and 2 stems from the four-year model of most North American medical schools, whereby the first two years are spent in a standardized classroom setting. Thirty-six students of 110 completed the survey and 10 completed focus groups.

Design

This was a two-part methods study about IDD education at the University of Toronto MD Program. The first component of our work was a needs assessment survey to explore: (i) Previous experience with people with IDD; (ii) Basic knowledge about IDD; (iii) Attitudes toward people with IDD within a clinical setting; (iv) Interest in a medical career with a focus on IDD; and (v) Preferred ways of learning about IDD (Table 1). The survey was generated via Google Forms, and issued via email to all MAM year 1 and 2 students (*n* = 110) in January 2017. There were no specific exclusion criteria. Participation was incentivized via a $2 donation per survey completed to a local IDD service organization.

Table 1 - *Needs assessment survey questions*

Question category	Item
Previous exposure to IDD	Q1: What sort of experience/exposure do you have to intellectual and developmental disabilities (IDD)? Please check off all that apply ● Minimal/none ● Immediate family member(s) or family friends ● School peer(s) ● Employment-related ● Clinical placement / clinical experience (e.g. as part of professional degree) ● Volunteering (e.g. summer camp) ● Post-secondary coursework (university- or college-level courses) ● Research projects ● Other (please specify)
Knowledge assessment	Q2: True or False? ● People with IDD are typically institutionalized (e.g. psychiatric hospital), as they are unable to care for all of their ADLs (activities of daily living, e.g. independent bathing) and IADLs (instrumental activities of daily living, e.g. banking). (F) ● An IDD must be present/evident before the age of 18. (T) ● People with IDD tend to have more complex/overlapping health needs (T) Q3: Which of the following terms is/are synonymous with “intellectual/developmental disability” ● Intellectual disability (Yes) ● Learning disability (No) ● Developmental delay (Yes) ● Mental retardation (No longer)

	- All of the above (No) - None of the above (developmental disability is the only appropriate term) (No) Q4: Which of the following diagnoses fall under the category of IDD? Please check off any terms that apply. - Down Syndrome (Yes) - Dyslexia (No) - Fragile X Syndrome (Yes) - ADHD (Attention Deficit Hyperactive Disorder) (No) - ASD (Autism Spectrum Disorder) (Yes) - Williams Syndrome (Yes) - All of the above (No) - None of the above (No) Q5: In what way(s) (if any) would you change your communication style when caring for someone with an IDD? How would this change if the patient came accompanied by a caregiver?
Attitudes assessment	Q6: On a scale of 0-10, to what extent do you feel **COMFORTABLE** interacting with someone with an IDD? Q7: On a scale of 0-10, to what extent do you feel **CONFIDENT** communicating with someone with an IDD in a clinical setting? Q8: On a scale of 0-10, to what extent do you feel **COMPETENT** in obtaining a clear history from someone with an IDD?
Future practice	Q9: At this point in time, what specialty/specialties are you considering for your future practice? Please check off any that you are somewhat seriously considering. - Family Medicine - Pediatrics - Internal Medicine - Psychiatry - Obstetrics & Gynecology - Surgery - Emergency Medicine - Other (please specify) Q10: To what extent do you *anticipate* caring for people with IDD in your future practice? - Not at all - Minimally

	- Somewhat - Quite a bit - A lot Q11: To what extent are you *interested* in caring for people with IDD in your future practice? - Not at all - Minimally - Somewhat - Quite a bit - A lot
Medical education	Q12: What sort of exposure/training do you hope to get about developmental disabilities in your PRECLERKSHIP training? Check off any or all that apply. - Theoretical information / lectures about developmental disability - In-hospital clinical skills training - Community-based clinical skills training - Ethics seminar with regards to the care (and challenges thereof) of developmental disabilities - Videos featuring people with developmental disabilities sharing their stories - All of the above - None of the above

The second component of the project were focus groups targeted towards the sub-group of year 1 & 2 students who volunteered to take part in a 6-week seminar series with questions aimed at understanding students’ experiences, key learning points, and any attitudinal changes (Table 2).

Table 2 - *Focus group questions*

Questions
1. How comfortable are you currently in caring for an individual who lives with developmental disabilities? 2. What challenges do you foresee in interactions with such individuals? 3. What was your motivation behind attending the MAM IDD seminar series? What did you hope to get out of this seminar series? 4. How have you attitudes and views towards individuals with developmental disabilities changed after the seminar series? 5. How would you rate your confidence levels caring for Individuals with IDD now? Compare this to how you felt about this before the seminar series? 6. What are the key points or pieces of information you took away from the seminar series?

Focus groups took place in April and May 2017, following completion of the DDSS. All participants who completed ≥5 of the 7 seminar series sessions were invited to take part. Focus groups were facilitated by the first author and lasted 45-60 minutes. A standardized script was used to introduce the participants to the focus groups, followed by six standardized questions. The focus group discussions were recorded using a mobile application, anonymized, and transcribed verbatim. Focus groups were chosen over individual interviews in order to allow for interaction and discussion among participants to provide a deeper and richer exploration of experiences (Kitzinger, 1995).

Data Analysis

Survey responses were summarized and analyzed using descriptive statistics. Focus group transcripts were coded independently by two of the investigators (MIJ and AC), and analyzed using a generic qualitative descriptive approach (Sandelowski, 2000). An inductive, iterative thematic analysis was applied to the transcripts in order to identify emerging patterns and themes (Strauss, 1987). Any points of disagreement or ambiguity were identified and resolved through a consensus discussion between the two coding authors. Lastly, representative quotes were selected to illustrate main themes.

Research Ethics

All components of this project were approved by the Health Sciences Research Ethics Board of the University of Toronto (protocol #33865).

Results

Survey Findings

A total of 36 students completed the survey (overall response rate 33%).
Forty-four percent of students reported minimal or no previous exposure to people with IDD. Of those with prior experience, 42% mentioned volunteer work, 25% mentioned school peers with IDD, and 19% had one or more immediate family members with IDD. In terms of basic IDD knowledge, almost all students were aware of deinstitutionalization efforts (92%) as well as the complex health needs – and comorbidities – of people with IDD (97%). The most common responses to an open-ended question about ways student would adapt their communication style were: ensuring the conversation was patient-centred, using simpler language, alternative methods of communication and speaking slower.

On the “attitudes assessment” component of the survey, students were asked about their interactions with IDD in a clinical setting. Mean ratings were highest for comfort, followed by confidence and competence (mean ratings of 5.8, 4.7 and 3.9, out of 10, respectively).

In response to the question about the degree to which they *anticipate* having to provide care to patients with IDD**,** all students recognized that people with IDD will make up a portion of their patients, with 44% expecting to work “quite a bit” or “a lot” with people with IDD. With regard to their future interests 17% reported no or minimal interest working with people with IDD, 75%

were “somewhat” or “quite a bit” interested, and 8% reported “a lot” of interest in being health care providers for people with IDD. Finally, students were asked about the types of educational approaches they would find most helpful when learning about IDD. Overall, there was no one teaching strategy that stood out as particularly favourable, with classroom teaching, clinical skills teaching, community visits, and video narratives of people with IDD all having similar rates of endorsement.

Focus Group Findings

There were a total of ten participants in the focus groups (six females), eight Year 1 and two Year 2 students. Overall, the participants were able to reflect on their experience in the seminar series and provide feedback surrounding their experiences, learning outcomes, as well as attitudinal changes. The findings reported here are based on the major themes that emerged from the focus groups and are supplemented by representative quotes from participants (identified via alphanumeric code).

Theme 1: Universality of Communication Skills

Many participants acknowledged the challenge of communicating with people with IDD as well as the issues that arise from having a caregiver present. The skill that they identified as being most useful in this context was to use an approach that is patient-centred, much like they would for any other neurotypical individual they are interviewing.

> “Before the seminar series I [thought] that perhaps you require a lot of skill and practice in order to work with this patient population. But after the seminar series I understood that really it’s the same patient-centred approach that we apply everywhere else.” (Participant A8Z)

One sub-theme that emerged was the factor of lack of time being a significant barrier to establishing effective communication with this patient population, especially when requiring other non-verbal communication methods.

> “One thing that we didn’t talk about was, that came up a lot I think in the series, was the idea of the length of the visit; how long an appointment should be and typically how maybe one is 10 minutes but that’s not enough when you are interacting with somebody with a disability.” (Participant 4P6)

Finally, students identified a number of communication tips and strategies that they learned during the seminar series. This included using open-ended and friendly communication; maintaining an open and welcoming environment; appropriately addressing caregiver concerns; and probing for root causes of issues.

Theme 2: Understanding of an Approach to Behaviours

There are several behaviours exhibited by people with IDD which may be perceived as disruptive. Participants were able to recognize that part of “treating” challenging behaviours is understanding that all behaviours are a means of communication:

> “Behaviours that might seem irrational and have no basis are actually indeed rational. They usually stem from like a change of the patient’s routine, something that might be bothering them, and that like these aren’t things that you should get frustrated with but rather things to kind of explore with like a logical structure.” (Participant L6M)

Theme 3: Appreciation for Community Resources and Team Based Approach to Care

Community resources was a theme that came up from a majority of focus group participants. Several participants reported an increase in their comfort levels with regard to caring for patients with IDD, knowing that these community resources are in place. In addition, there was also some discussion around the fact that even though these resources exist, their availability does not seem to meet the requirements of all patients with IDD.

> “From different workshops we see that there are multiple resources that are available in the community, and although limited, each resource forms a puzzle piece that help to take care of the individual patients.” (Participant WI6)

Students also commented on the importance of other allied health professional and resources as an adjunct to the role of the physician in caring for people with IDD.

> “I think one of the biggest points like that I took was that it takes like an entire team to care for people with disabilities in such a multidisciplinary field that to expect to be able to like [laugh] tackle all different challenges on your own is beyond what anybody can do.” (Participant T5V)

Finally, students recognized the inherent value of community resources for the social wellbeing and connectedness of people with IDD.

> “And then there was one interaction ... when the young girl said that she wished that another girl in her family had been born like she was and so that made me I guess feel even more empathy for people’s intellectual disabilities and that they want a community.” (Participant T5V)

Theme 4: Value of First-Hand Exposure

Several participants noted that it was very valuable for them to converse with and interact with people living with IDD and that it provided context and perspective that could not be found elsewhere.

> “Something that really helped was the exposure that we had both here when we had patient guests come in and both when we visited for example [the treatment centre for kids with IDD and their families].… I feel like that contact is something I couldn’t have read about so I was very thankful for having that opportunity.” (Participant A8Z)

Discussion

Previous research has highlighted the health disparities experienced by people with IDD and identified inadequate training – whether of physicians or other healthcare providers – as a contributing factor (Wilkinson, Dreyfus, Cerreto, & Bokhour, 2012). With this study, the goal was to combine descriptive information about medical student needs with qualitative feedback on a subgroup's perceptions on what was most helpful. Overall, findings from this study suggest that current medical students are aware of the importance of community-based care of people with IDD, with the majority reporting a commitment to providing healthcare and developing their skills further. To that end, the seminar series was a useful introduction to the needs of the IDD population.

The results of the needs assessment survey highlighted a few key points. First, students had a reasonably good basic knowledge of IDD, and were able to list some helpful communication strategies that they could use in a clinical setting. This may, in part, be a reflection of some students' prior experience with people with IDD through school, home, or volunteer work. With regards to attitudes and degree of preparedness students rated themselves higher on perceived comfort than they did with regards to perceived competence and confidence. This is similar to a prior study of first year medical students who rated overall comfort scores higher than confidence and competence scores following a blended learning activity (Coret et al., 2018). This was to a large extent anticipated, as these three constructs are meant to represent progressive milestones in one's preparedness to provide medical care to this patient population. Finally, when asked about their future practice, 83% of students stated they were somewhat, quite, or very interested in working with the IDD patient population. While these numbers are mere approximations of actual career interests they nonetheless capture a rather positive underlying attitude toward people with IDD.

With regards to the post-series focus groups, participants highlighted a number of key themes and take-away learning points. They discussed, for example, the importance of communication (specifically person-centred communication), the development of an approach to analyzing challenging behaviours, the value of knowing what community resources are available to assist physicians in the care of people with IDD, as well as an appreciation for experiential learning via first-hand exposure with people with IDD. In addition, one of the major challenges that students reported that they might have going forward in interactions with people with IDD was communication, especially in a time-constrained environment.

Given that one of the major difficulties faced by people with IDD is communication barriers, it is not surprising that many medical students highlighted this to be a core issue. People with IDD have a vast range of expressive capabilities and may use a variety of verbal and non-verbal techniques. The majority of preclinical training around communication skills involves practicing with neurotypical patients who speak English and are not impaired in their ability to communicate. As such, students found it quite beneficial to be able to learn about and engage with people with IDD.

Our findings – namely, that experiential learning through first-hand exposure is valuable for medical learners – replicate those by other researchers. A systematic review by Shakespeare and

Kleine (2013) looked at a variety of educational interventions surrounding disabilities and found that lectures were less effective in changing learner attitudes compared to more experiential methods. This benefit is seen in a number of studies and show that engaging with people with IDD results in an improvement in the learners' confidence, understanding, attitudes (Tracy & Iacono 2008; Rillotta & Nettelback 2007; Coret et al., 2018). This is in keeping with the results from the focus groups where students found the exposure to people with IDD to be very beneficial.

Students from the seminar series appreciated learning about community resources, recognizing that greater awareness of available supports would in turn make them far more comfortable as future physicians caring for these patients. That having been said, learners expressed concern about the limited availability and accessibility of many existing resources — particularly for adults with IDD. These realities may be a broader reflection of fragmented healthcare systems and policies in Ontario and elsewhere (Ombudsman Ontario, 2016), and are a barrier to more experienced health care providers as well (Selick, Durbin, Casson, Lee, & Lunsky, 2018)

Limitations and Future Directions

The primary limitation of this work stems from the relatively small sample of subjects studied, be it for the needs-assessment survey (*n* = 36) or the focus groups (*n* = 10). As such, the findings may not be truly representative of preclinical medical students' attitudes toward IDD or their experiences of learning about people with IDD. Futhermore, the survey captures student attitudes at only one point in time (pre-clinical years); it may be worth exploring how students' views and perspectives change later in medical school, and whether participation in such a series had any impact on career choices later on.

Inherent to the small sample size is also the very nature of the seminar series, namely, an extra-curricular *elective* activity. Given the relevance and success of this pilot project, there is room for growth through both dedicated curricular time and experiential learning opportunities within the University of Toronto MD Program.

Finally, one must be mindful of the interprofessional approach needed for the care of people with IDD. While this study focused on preclinical medical students, other disciplines (e.g., nursing, social work, occupational therapy, dentistry) may benefit from similar interventions tailored to the needs of their trainees. Ultimately, it is our wish to see people with IDD have timely access to person-centred and holistic care — both across their lifespan and across the range of healthcare services.

Key Messages from this Article

People with disabilities. You are insightful and capable advocates for your own needs and have the potential to offer valuable teaching to health professionals and health professional students.

Health professionals. There is a lot to be learned about intellectual and developmental disabilities, but unfortunately, students in health professions programs have limited exposure to this area. We encourage ongoing curricular and extra-curricular program development to bridge this gap.

Messages clés de cet article

Personnes ayant une incapacité. Vous êtes des défenseurs perspicaces et compétents de vos propres besoins. Vous avez le potentiel d'offrir un enseignement de valeur aux professionnels de la santé et aux étudiants du secteur de la santé.

Professionnels de la santé. Il y a beaucoup à apprendre à propos de la déficience intellectuelle et développementale. Malheureusement, les étudiants du secteur de la santé ont peu de contact avec ce sujet. Nous encourageons le développement continu des programmes scolaires et extrascolaires actuels pour combler cette lacune.

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Glossary Terms

Intellectual and developmental disabilities (IDD) are defined as conditions that: **(i)** hinder one’s ability to learn, understand, or use information; **(ii)** affect social and language skills; and **(iii)** prevent one from being able to function fully independently and complete necessary tasks for daily living. Moreover, IDD are characterized by **(a)** being present at birth or having an onset before the age of 18; **(b)** being permanent; and **(c)** ranging from mild to severe.

Source: Developmental Services Ontario. What Is A Developmental Disability? (2016). Retrieved January 30, 2018.