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Need for Prominent Core Curricula Designed and Taught by Persons with Disabilities in All Levels of Medical Education

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Abstract

The need for comprehensive core curricula in medical education regarding the health of persons with disabilities has been identified by disability scholars for many years and was recently reinforced by our research indicating Canadian physicians lack knowledge of the social model of disability, and their legal duty to ensure accommodation for persons with disabilities to have equal access to health. The purpose of the current research is to investigate the existence of core medical education curricula devoted to the health of persons with disabilities and determine whether persons with disabilities were involved as curricular designers and educators. A comprehensive literature search of all academic sites found few papers reporting on such curricula, and the time devoted to these curricula was small. Only one medical school internationally was found to have persons with disabilities playing a major role as curricular designers. Further problematic was that "disability" tended to be portrayed by non-disabled professional actors hired as standardized patients (SPs), and only occasionally by actors with disabilities but in scripted SP roles distant from their lived experience. We contend that if persons with disabilities designed medical curricula, non-disabled SPs would be replaced by persons with disabilities as medical educators, sharing their own lived experiences. Another alternative in replacing professional able-bodied actor SPs is the novel education method of digital storytelling, with disabled persons sharing their lived experiences. Another immediate opportunity exists in Canada in the newly developing competency-based curricula for prominent core competencies to be designed and taught by persons with disabilities.

Key Words

Medical Education, Health of Persons with Disabilities, Core Curriculum, Ethics of Non-Disabled Actor SPs

Introduction

The need for curricula in medical education regarding persons with disabilities has been identified by disability scholars for many years (Dolmage, 2017; Iezzoni & Long-Bellil, 2012; Linton, 1998; Long-Bellil et al., 2011; Minihan et al., 2004; Rice et al., 2017). This need was recently reinforced by our research (Joseph et al., 2018) in which the Canadian physicians interviewed displayed lack of knowledge of the social model of disability (Dolmage, 2017; Nisker, 2019; Oliver, 1990; Shakespeare, 2006; Shakespeare et al., 2009), as well as their legal duty to ensure accommodation for persons with disabilities. Such lack of accommodation is discrimination under Canada's Charter of Rights and Freedoms (Canadian Charter of Rights and Freedoms, 1982), provincial human rights codes (Human Rights Code, R.S.O. 1990, c. H.19, 2018), and the United Nations Convention of the Rights of Person with Disabilities (Convention on the Rights of Persons with Disabilities, 2006). Rather, the physicians interviewed thought themselves "kind" because of the extra time they gave to women with disabilities, whom they viewed as "a problem" for the time-efficiency of their practices (Joseph et al., 2018). The physicians interviewed in our study (Joseph et al., 2018) and in American studies (Smeltzer et al., 2018) drew attention to their lack of any training regarding persons with disabilities.

From our perspectives as physicians with backgrounds in medical education, ethics and health policy, we contend that a curriculum regarding persons with disabilities should be added as a prominent and comprehensive core curriculum in all medical schools, consistent with attributes of prominent core curricula in most Canadian medical schools, including: (i) mandatory for all students; (ii) substantial commitment of hours; (iii) assessment processes that require successful achievement before the medical student or resident progresses to the next level of education or graduates; (iv) appreciated by medical learners as being essential to their ability

to practise good medicine; (v) involving dedicated educators with expertise in the area they are facilitating; and (vi) acknowledged as important by the deans responsible for medical education. Specifically regarding the health of persons with disabilities, we agree with disability scholars that such curricula must be designed and taught by persons with disabilities (Sarmiento et al., 2016; Shakespeare, 2006; Shakespeare et al., 2009), and focus on the social model of disability (Dolmage, 2017; Nisker, 2019; Oliver, 1990; Shakespeare, 2006; Shakespeare et al., 2009).

The purpose of the current research is to investigate the world literature regarding prominent and comprehensive core curricula devoted to the health of persons with disabilities.

Literature Search

A comprehensive literature search of all academic sites, including PubMed and Ingenta, was conducted, using the search terms "medical education curricula" AND "disabilities"; "standardized patients"; "social model of disability"; "online teaching"; "competency-based medical education"; "pseudo-immersion"; "intersectionality". Few papers were found that describe medical education curricula dedicated to persons with disabilities (Long-Bellil et al., 2011; Minihan et al., 2004; Sarmiento et al., 2016; Symons et al., 2009), and the time devoted in these curricula was only several hours. There were no medical curricula in which the social model of disability either replaced the medical model of disability or was taught alongside the medical model of disability. At only one medical school were persons with disabilities playing a major role in designing and teaching the curriculum, and this medical school was in the United States (Sarmiento et al., 2016). We found no curricula that would be considered prominent and comprehensive core curricula to satisfy the above criteria consistent with prominent core curricula in most Canadian medical education programs.

Standardized Patients (SPs)

Medical students in many countries are increasingly learning through simulated cases where actors portray "standardized patients" (SPs). This indeed is true in medical curricula regarding persons with disabilities, in which disability tended to be portrayed by non-disabled professional actors who were hired as SPs (Long-Bellil et al., 2011; Minihan et al., 2004; Symons et al., 2009). Persons with disabilities were occasionally also used as SPs, but generally required to give scripted performances distant from their lived experiences (Long-Bellil et al., 2011; Minihan et al., 2004; Symons et al., 2009). At one American medical school, when persons with disabilities are used as SPs, they also have the opportunity to respond to questions regarding their personal experience and are thus considered "medical educators" (Minihan et al., 2004).

In seven other American medical school curricula that used SPs, Long-Bellil and coauthors found that the SPs again were almost always non-disabled actors portraying persons with disabilities, and in the few instances when persons with disabilities were the SPs, the conditions they portrayed were distant from their lived health and social experiences (Long-Bellil et al., 2011). The authors indicated that non-disabled actor SPs were better for "reliability (i.e., consistency) between performances," as they give the same history and physical findings to each student, and this consistency was important to ensuring delivery of the goals of the SP encounter, as well as representing a fair and effective evaluation of medical students (Long-Bellil et al., 2011, p. 1168). The authors also commented that using non-disabled actor SPs obviates the "operational challenges" that occur when using SPs with disabilities, such as the difficulty in recruiting disabled persons "with the skills to perform the SP role," and the "challenges that individuals with disabilities confront in their daily lives—ranging from fluctuating health status

to transportation difficulties" (Long-Bellil et al., 2011, p. 1168). As the authors are advocates for

inclusion of persons with disabilities, their comments, we believe, reflect the reality in medical

education, rather than what the authors believe should be in medical education.

Other Than SP-Based Curricula

Rather than relying solely on the use of SPs, one American medical school curricula,

developed with the participation of "disability advocates," uses small group sessions and "video

and in-person narratives of individuals with disabilities" sharing their own lived experiences

(Sarmiento et al., 2016, p. 954). This model has been praised as reflecting "nothing about us

without us" (Charlton, 1998; Sarmiento et al., 2016). Other medical curricula use a combined

approach, for example, a one-day experience in a primary care "facility" (the word "facility" in

scare quotes because facilities are rarely home-like) for patients with disabilities, along with

didactic teaching and SPs (Symons et al., 2009). However, there appears to be little time devoted

to persons with disabilities sharing their lived experiences. The time allotment in these models

(usually less than 10 hours) is small compared with standard core medical curricula (Sarmiento

et al., 2016; Symons et al., 2009).

In some Canadian medical schools, the strategy of pseudo-immersion is being used to

place non-disabled medical learners in the position of persons living with disabilities (Leo &

Goodwin, 2016). The pseudo-immersion strategy involves medical students wearing distorting

goggles, walking around in swim-flippers, and using wheelchairs, to experience what it may be

like living with a disability. Although pseudo-immersion may seem like a nod to inclusion of the

health of persons with disabilities in their curricula, this strategy has been criticized as

ineffective (Leo & Goodwin, 2016). Though Nario-Redmond and coauthors (2017) found that

pseudo-immersion strategies simulating disabilities do not promote positive attitudes toward

persons with disabilities, participants did report better understanding of the position of disabled persons.

Online Modules

Online modules are increasing in popularity in medical education (Cook et al., 2008; Evans et al., 2017; Giroux & Moreau, 2020; Metcalf et al., 2010; Pei & Wu, 2019; Regmi & Jones, 2020; Subramanian et al., 2012; Wilson et al., 2004; Zhang et al., 2017). Some researchers claim that online modules are as effective as "off-line learning", and also have advantages (Cook et al., 2008; Pei & Wu, 2019; Subramanian et al., 2012). For example, Subramanian and coauthors (2012) found that a web-based medical learning modality demonstrated "a significant improvement in student learning retention compared to traditional didactic lecture", and Pei and Wu (2019) found no advantages of in person learning compared to online learning. However, although online modules on caring for persons with disabilities are increasingly being used in place of first-person engagement, we found no papers clearly demonstrating such online modules are effective in increasing the understanding of medical learners regarding persons with disabilities. Rather, Wilson and coauthors (2004) report that diversity can be "masked in an online setting" (Wilson et al., p. 7). Also to the contrary, "the masking of these identities can make it less obvious that particular learners' needs are not being addressed, which may lead to implications for full participation in online and blended courses" (Evans et al., p. 346).

Competency-Based Medical Education

We found no evidence in our literature search of articles regarding Canada's newly developing Competency-Based Medical Education (CBME) curricula of the notion of competency regarding the health of persons with disabilities being included as a core competency. Ankam and coauthors (2019) reporting on the longer-standing CBME curricula in

the United States write that a gap exists in medical student "training in the care of people with disabilities … to adequately meet the competencies that underlie the Core Entrustable Professional Activities for Entering Residency" (p. 781). These authors also bring attention to a survey by Seidel and Crowe (2017) in which 48% of responding deans of American medical schools reported no "disability awareness curriculum," and that many medical schools lacked any "elements addressing disability."

Discussion

Concerns with Non-Disabled Actor SPs

We contend that the use of non-disabled actor SPs to portray persons with disabilities is disingenuous and promotes ableism (i.e., discrimination favouring non-disabled people), as it assumes that no persons with disabilities can satisfy the goals and objectives of the educational experience as designed by non-disabled educators. Use of non-disabled actor SPs also denies actors with disabilities the opportunity to perform their craft, similar to the problematic use of non-disabled actors in cinema or theatre to portray persons with disabilities (Hawkins, 2015; Jordan Harris, 2014). Using non-disabled actors promotes the concept that no disabled actors have the capability to perform these roles, and thus promotes ableism. When given the opportunity, actors with disabilities have demonstrated their capacity to perform brilliantly in complex roles (Hawkins, 2015; Jordan Harris, 2014).

Concerns with Scripted Performances by Disabled Persons

We also have concerns when persons with disabilities have the rare opportunity to perform SP roles because, by definition, SP roles require scripted or semi-scripted performances to align with the goals, objectives and learner-evaluation of the particular course. Although

scripted performances may make it easier for non-disabled curriculum designers and evaluators to satisfy the objectives of the course, such performances lack the power of validity and verisimilitude inherent in sharing true medical and social experiences. Scripted performances also deny persons with disabilities the opportunity to share their lived health and social experiences. We believe the educational potential for medical learners is much higher when persons with disabilities tell their own stories, answer questions and recommend changes. Indeed, engaging medical learners with the personal observations and feelings of a disabled person in our health and social systems is essential to expanding the understanding of medical learners, and increasing their awareness of how persons with disabilities perceive themselves and want to be perceived.

Although using SP actors with disabilities is preferable to non-disabled actors portraying persons with disabilities, it is essential that the medical trainees are clearly aware at each encounter that the performance of an SP actor with disabilities is fictional, and the more important part of the learning will occur when the SP with disabilities shares her true experiences in our health and social systems following the performance. Further, the medical learners should understand in advance that they will have the opportunity to ask questions of the person with disabilities, and there will be sufficient time for an in-depth discussion based on the responses. It is also imperative that as part of any medical educational process, the SP actor with disabilities be permitted to offer suggestions for improvement in accommodation toward the health of persons with disabilities, and help ensure future and current physicians are aware of their legal duty to advocate for such accommodation. We believe that in the development of prominent core curricula regarding the health of persons with disabilities that information regarding the legal duty of physicians to accommodate persons with disabilities be an important part, and that

disability scholars, including those with backgrounds in law, develop the scripts for disabled-actor SPs, and provide short background summaries of the law in this area in Canada, and in other countries where such curricula may in the future be developed. Such information developed by legal scholars must be vetted by disability scholars prior to being presented to medical students.

The challenges in using SP actors with disabilities brought to our attention by Long-Bellil and coauthors (2011), include "operational challenges," such as the difficulty in recruiting disabled persons "with the skills to perform the SP role" and the "challenges that individuals with disabilities confront in their daily lives—ranging from fluctuating health status to transportation difficulties" (p. 1168). However, these challenges can be overcome with increased funding of the education experience, and with greater motivation on the part of curricular designers and deans of medical schools. Increased funding, for example, could provide better transportation for persons with disabilities to more easily access medical schools, and could also foster an increased number of persons with disabilities being available as educators, so that if a person with disabilities happens to be ill on one of the days when she was to be an educator, alternates could access transportation to be at the learning location.

Concerns with Increasing Use of Online Modules

Although online modules are increasingly replacing first-person engagement in medical education because they are inexpensive and easy to implement (Cook et al., 2008; Evans et al., 2017; Metcalf et al., 2010; Pei & Wu, 2019; Subramanian et al., 2012; Wilson et al., 2004; Zhang et al., 2017), we contend that they are formulaic, lack intimacy and often allow users to "click through" without absorbing the material, making it a much less effective engagement strategy. Lack of proven effectiveness of online modules, as well as their potential to "mask

diversity" (Wilson et al., 2004, p. 7), hinders the learning experience, and reinforces our

contention that personal engagement with persons with disabilities should continue. It is possible

that online modules when designed and taught by persons with disabilities that share the health

and social experiences of persons with disabilities may be more appropriate than in-person

performances by non-disabled actor SPs portraying persons with disabilities. However, in our

experience online interaction does not engage medical learners to the same extent as first-person

encounters, in which persons with disabilities share their own health and social experiences with

medical learners.

A novel alternative to online modules is multi-media storytelling in the classroom, an

arts-informed method wherein persons with disabilities speak to medical learners through digital

storytelling (Rice et al., 2018). Multi-media storytelling would be a good addition to medical

education, as part of a comprehensive core curricula involving persons with disabilities , even if

additional funding is required. Multi-media storytelling could also extend to other areas of

medical education.

Inclusion of Social Model of Disability in Medical Curricula

It is essential that the social model of health and the social model of disability (Dolmage,

2017; Nisker, 2019; Oliver, 1990; Shakespeare, 2006; Shakespeare et al., 2009) be included with

the medical model in all levels of medical education. By including the social model of disability

when developing comprehensive and prominent core medical curricula regarding the health of

persons with disabilities, the planning-thinking of non-disabled curricular designers will expand,

as will the thinking of medical learners. The lack of knowledge among physicians regarding the

social model of disability was illustrated in the comments of the academic physicians in our

previous research (Joseph et al., 2018). The lack of awareness of most Canadian physicians

regarding the social model of disability insists the necessity of comprehensive core curricula on the social model of disability be prominent in all levels of medical education. Moving beyond a social model of disability to a social model of medical education, replacing the too long-standing and paternalistic traditional medical model, is essential not only for the health of persons with disabilities but for all persons in all practices and communities, as emphasized in the importance of "social determinants of health" (Frazee et al., 2002; Mykitiuk & Nisker, 2010; WHO, 2010).

It may be challenging for non-disabled physicians trained in curricular design, who believe themselves to be experts in medical education, to understand the necessity of persons with disabilities becoming designers and educators. This raises another issue related to disability and medical education, the fact that persons with disabilities have been greatly underrepresented in medical school classes (Gault et al., 2020; Meeks & Herzer, 2016). Indeed in the United States, while 20% of the general population report having a disability, only 2% of physicians report having a disability (DeLisa & Thomas, 2005; Gault et al., 2020), and less than 3% of medical students report a disability (Gault et al., 2020; Meeks & Herzer, 2016). One of the ways to mitigate this problem would be admit many more persons with disabilities into medical schools, some of whom may choose to be medical educators. Persons with disabilities as medical educators could better design medical curricula promoting understanding of the positions of persons with disabilities.

Competency-Based Medical Education

Competency-based medical education (CBME) began developing in the late 1990s in the Netherlands (Bleker et al., 2004), and by the Accreditation Council for Graduate Medical Education in the United States (Swing, 2007). According to ten Cate (2005), "problem-based learning," a system initiated by Canada's CanMeds 2000 initiative (Frank, 2005), was a

forerunner to CBME. CBME, currently being rolled out in Canada under the recently changed name of "Competence by Design," is proposed to ensure medical graduates have the skills to practise, and to serve as an educational tool for continued learning (RCPSC, 2018). Ten Cate (2005) suggests competencies "should be (a) specific, (b) comprehensive (i.e. include knowledge, attitude and skill), (c) durable, (d) trainable, (e) measurable, (f) related to professional activities and (g) connected to other competencies." Through the first half of 2020, however, we have found no evidence of a competency regarding the health of persons with disabilities.

We contend that in addition to the competencies outlined by ten Cate (2005), the medical learner must display knowledge of the social model of disability (Dolmage, 2017; Nisker, 2019; Oliver, 1990; Shakespeare, 2006; Shakespeare et al., 2009). When persons with disabilities design and facilitate the newly developing competencies in Competency-Based Medical Education (now Competence by Design in Canada), medical learners will graduate only after they have demonstrated competency in understanding that it is the legal right of persons with disabilities to be accommodated to have the same access as that of non-disabled persons, and that failure to provide equal access is considered discrimination (Canadian Charter of Rights and Freedoms, 1982; Canadian Human Rights Act, RSC 1985, c H-6, 1985; Convention on the Rights of Persons with Disabilities, 2006; Human Rights Code, R.S.O. 1990, c. H.19, 2018). Another required competency would be that the medical learners display their understanding of how persons with disabilities perceive themselves and want to be perceived.

Our research does not specifically acknowledge the perspective of the authors of the articles that we have referenced. Adding the perspective from which authors and their arguments come is important, but it is often not clear from the referenced article itself or from a search of

who the authors are. Our research did not explore how other marginalized identities, such as race, gender and class, might intersect with persons with disabilities in the development of a prominent core curricula. This intersectionality is important (Jaehn et al., 2020; Kline, 2020; Lett et al., 2020; Mocanu et al., 2020; Phillips et al., 2020), and it is hoped that researchers and scholars of other disciplines than ours might take this on in-depth after reading our article.

Conclusions

The use of non-disabled standardized patients portraying persons with disabilities should cease in favour of persons with disabilities sharing their lived experiences and providing recommendations for improvement in accommodation. Novel education methods, such as multi-media storytelling, should replace online modules in medical education as soon as possible, even if additional funding is required. The social model of disability must be included with the medical model of disability, in order that future physicians will appreciate that barriers to health are created by social and physical environments that do not accommodate persons with disabilities. Another immediate opportunity exists in the newly developing Competency Based Medical Education curricula (now called Competence by Design in Canada) to be designed and taught by persons with disabilities, yet we have found no evidence that this is occurring. Without persons with disabilities designing, teaching and evaluating these competencies, these curricula will be problematic, and physicians will continue to be nothing more than mechanics of the bodies of persons with disabilities. As it may be challenging for current medical curricula designers to appreciate the importance of a paradigm shift toward a social model of disability, it is only through including more persons with disabilities as designers of medical curricula that the

social model of disability can be realized. For this to be possible it is essential that more persons with disabilities must be included in every class in every Canadian medical school.

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