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A Curriculum of Caring for People With Developmental Disabilities in Medical Education

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Abstract

The Curriculum of Caring for People with Developmental Disabilities provides experiential learning to improve the capacity of healthcare professionals to deliver person/family-centred care to people who live with intellectual and/or developmental disabilities (ID/DD). The purpose of this project was to explore the impact of the curriculum on medical students' self-reported comfort, confidence, and competence in providing healthcare to the ID/DD population. The rationale for this study was to better understand how experiential learning (bringing people with lived experience into the medical school experience of trainees) might prepare future physicians to improve health care experiences for an underserved population.

*A three-phase experiential learning model: (1) early exposure, (2) clinical skills training, and (3) application in clinic settings, was introduced to undergraduate medical students (*n *= 28). (Phase 1 included 52 nursing students in an interdisciplinary half day program.) A pre-post survey was used to explore changes in self-reported comfort, confidence and competence on a five-point scale. A repeated measures ANOVA and subsequent post-hoc independent t-tests were used to analyze the data. Narrative comments complemented results at each phase.*

Participants' self-reported comfort, confidence, and competence increased significantly following Phase 1 ($p < .001$) and Phase 2 ($p < .001$). Post Phase 3 responses, were not significant. Student narrative comments were analyzed inductively using open-coding and overarching themes were coupled with participant quotes to accompany the analysis in each phase.

This study adds to the literature on ID/DD curricula in healthcare education. The Curriculum of Caring influenced students' perceived capacity to provide healthcare to the ID/DD population.

The Ministry of Community and Social Services (2008) defines a developmental disability (DD) as:

> significant limitations in cognitive functioning and adaptive functioning and those limitations originated before the person reached 18 years of age, are likely to be life-long in nature, and affect areas of major life activities such as personal care, language, skills, learning abilities, the capacity to live independently as an adult or any other prescribed activity.

The American Psychiatric Association (2013) describes an intellectual disability (ID) as "a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains." While definitions and diagnostic criteria are used for service eligibility, delivery, and research, there is recognition of heterogeneity of etiologies, presentations and needs that may change over the lifespan.

The Curriculum of Caring for People With Developmental Disabilities

Key Messages

Experience Matters

People with developmental disabilities can share their experiences to help health care students/ workers to do a better job of listening and caring for their needs.

Communication Counts

Health care students/workers can be taught how to Communicate CARE when they meet people with developmental disabilities.

Intellectual and developmental disabilities (ID/DD) can be associated with a range of medical and mental health conditions with potential dysfunction in multiple organ systems or functional realms: for example, sensory, neurological (Cooper, Melville, & Morrison, 2004; Prasher & Gomez, 2004; Van-Schrojenstein-Lantman-de-Valk, Metsemakers, Haveman, & Crebolder, 2000), gastrointestinal, metabolic (Bohmer, Klinkenberg-Knol, Niezen-de-Boer & Meuwissen, 2000; Melville, Hamilton, Hankey, Miller, & Boyle, 2007), and mobility (Cooper et al., 2004; Melville et al., 2007; Prasher & Gomez, 2004; Van-Schrojenstein-Lantman-de-Valk et al., 2000). People with ID/DD tend to have a higher prevalence of health problems than the general public (Cooper et al., 2004; Krahn, Hammond, & Turner, 2006), yet their health needs often go unrecognized and unmet (Cooper et al., 2004). An Ontario study highlights the urgency for adults with DD, who were more likely to frequent emergency rooms and less likely to access primary care (Centre for Addiction and Mental Health, 2013).

Barriers to identification of treatable conditions can be both patient and clinician related. Some patients with ID/DD may not fully appreciate the significance of their symptoms or be able to verbally describe them (Krahn et al., 2006; Van-Schrojenstein-Lantman-de-Valk, & Walsh, 2008). Healthcare providers report discomfort interacting clinically with patients who have an ID/DD, citing a lack of training and inexperience interviewing this population (Chew, Iacono, & Tracy, 2009). While medical professionals receive training in clinical and communication skills, teaching is generally focused on oral history taking without explicit emphasis on adaptations for people with ID/DD or other communication barriers. Medical education and ID/DD curricula can play a critical role in preparing physicians to adapt clinical approaches in order to meet the healthcare needs of patients with ID/DD and alternate communication styles (Minihan et al., 2004).

A report by the International Association for the Scientific Study of Intellectual and Developmental Disabilities and Inclusion International (2000) recommended that all nations ensure sufficient numbers of health professionals be trained in the care of individuals with ID/DD. In recent years, medical schools have used a variety of approaches to teach medical students about disabilities, including didactic lectures, small group interactions, and opportunities to shadow professionals who serve individuals with disabilities (Conill, 2008; Gosney, Storman, Geving, & Liu, 2009; Parkin & Stein, 2001; Voelker, 2002). Few Canadian and American medical schools report formally including specific ID/DD training as part of their curriculum, providing students with optional ID/DD training (Holder, Waldman, & Hood, 2009; Minihan et al., 2004). The Curriculum Assessment of Needs Project by The American Academy of Developmental Medicine and Dentistry (2004) indicated that 81% of medical students received less than three hours of formal DD education and 38% reported no formal training (Jurczyk & Kelly, 2009; Waldman, Fenton, Perlman, & Cinotti, 2005). Fifty-three percent of Deans who responded did not feel that their graduates were competent to treat people with ID upon graduation, and 56% of students did not feel competent to treat patients with an ID. There is recognition that most adult primary care physicians and subspecialists have not been clinically trained or operationally prepared to receive persons with significant developmental disabilities into their community practice settings (Jurczyk & Kelly, 2009).The challenge remains: how can students acquire adequate experience to feel capable of providing the necessary person-centred care to populations considered more challenging due to communication barriers and complex needs? There are programs designed to foster cultural competencies with other marginalized populations through exposure, longitudinal experiences, and mentorship (Huang & Malinow, 2010). Curriculum developers and planners have incorporated learning experiences into their programs that equip healthcare learners to become comfortable and better able to adapt healthcare to the needs of diverse patient populations (Kripalani, Bussey-Jones, Katz, & Genao, 2006; Long-Bellil, Robey, Graham, Minihan, Smeltzer, Kahn, & Alliance for Disability in Health Care Education, 2011; Woodard, Havercamp, Zwygart, & Perkins, 2012).

The Curriculum of Caring for People with Developmental Disabilities was developed by medical educators in partnership with developmental service providers and patient educators. In 2008, McMaster University, Michael G. DeGroote School of Medicine, and Niagara Regional Campus (NRC) partnered with Bethesda Services to provide students with opportunities to interact with people whose lives are affected by ID/DD. Brock University Health Sciences (Nursing and Department of Applied Disability Studies) joined as collaborators to further develop, implement and evaluate experiential learning interventions. Program evaluation (anonymous student feedback used to shape each phase of the Curriculum of Caring since the 2008 inception) was augmented by this preliminary study exploring the influence of the three phases of the Curriculum of Caring on undergraduate medical student self-reported comfort, confidence, and competence as healthcare providers to people with ID/DD.

Materials and Methods

Curriculum of Caring Overview

Phase 1: Early Exposure. Initial early exposure was designed as an interprofessional half-day for medical and nursing students in a community-based setting for children and adults with DD (Bethesda Services, Niagara region, Ontario). Medical (*n* = 28) and nursing (*n* = 51) students completed pre-session questionnaires. Faculty of medicine and nursing facilitators prompted small groups of eight to nine medical and nursing students to share experiences working with people with DD. The small groups then rotated among four 30-minute experiences: (1) three to four volunteer hosts from Bethesda's Adult Day Program discussed their lives and answered questions; (2) an interactive, introductory overview of ID/DD was

Table 1. Curriculum of Caring for People with Developmental Disabilities: Three Phases of Experiential Learning

Curriculum of Caring	*McMaster University Undergraduate Medical Education Program*	*Niagara Regional Campus Medical Students* n = *28*
Phase 1: Early Exposure in first year	• Interprofessional half day with nursing students	Pre-Post session questionnaires, narrative comments
Phase 2: Clinical Skills pre-clerkship	• Small group Intro to Communicate CARE & Interviews	Pre-Post session questionnaires, narrative comments
Phase 3: Clinical Application during psychiatry clerkship	• Student placement with preceptor working with interdisciplinary teams for youth and adults with ID/DD	Optional post questionnaire with narrative feedback

provided by a specialist physician and nurse; (3) a Community Networks of Specialized Care facilitator led a case-based discussion, introducing the Canadian Primary Care Practice Guidelines for ID/DD (Sullivan et al., 2011); and 4) a mother of a child with ID/DD shared family experiences (https://machealth.ca/programs/curriculum_of_caring/m/mediagallery/1867). All students participated in group reflective discussions followed by post-session questionnaires.

Phase 2: Clinical Skills Interviewing. Clinical skills training was provided for all NRC medical students (*n* = 28) prior to clerkship. Medical students visited a Bethesda Services clinic setting in groups (n = 7-8). A Curriculum of Caring clinical skills primer was presented, highlighting adaptations for interviews with persons with ID/DD: Communicate C.A.R.E. (Clearly, Attentively, Responsively, Engaging the person first and others as appropriate). For more information see Curriculum of Caring for People with Developmental Disabilities (n.d.). Students had opportunities to interact with four volunteer patients (two students per patient for approximately 20 minutes). The volunteers had varying cognitive, communication, and mental health profiles. Some had caregivers present. Students were instructed to interact with the volunteers/caregivers, learn about their particular health and/or mental health needs and make be prepared to discuss observations. These interviews were followed by facilitated group discussions with the clinical skills preceptor, focusing on the interviewer's experiences and what they learned from and about the people they interviewed.

Phase 3: Application. Application of "Communicate C.A.R.E." and clerkship level competencies took place in various clinic settings, with the most focused ID/DD experience during their psychiatry clerkship rotation. The psychiatry clerks (*n* = 28) worked with interprofessional teams at community-based clinics for children and adults with ID/DD and varied healthcare needs. The psychiatric preceptor provided clinical experiences that included opportunities to participate in interviews, patient care, and team discussions. Students encountered patients with ID/DD in other clinical settings such as a pediatric rehabilitation centre; however, these experiences were not formally tracked or evaluated. At the conclusion of clerkship, medical students (*n* = 14) volunteered to complete post-questionnaires with narrative comments.

Study Population

Undergraduate medical students (*n* = 28) participated in all three phases of the Curriculum of Caring. Senior nursing students (*n* = 51) participated in the initial phase (interprofessional half day). The same cohort of medical students participated in all three experiential learning interventions; however, due to anonymity of the survey responses, within-subject analyses could not be conducted. The Joint Research Ethics Board of McMaster University Faculty of Health Sciences, Hamilton Health Sciences and St. Joseph's Healthcare Hamilton approved this study (File #15-174).

Study Design

A pre-post study design was used to evaluate changes in participants' comfort, confidence and competence after exposure to the Curriculum of Caring program. Questionnaires were administered to participants pre and post Phases 1 and 2. Medical students were invited to complete a post questionnaire at the end of clerkship (Phase 3). Participants used a 5-point Likert Scale (1 = *strongly disagree* to 5 = *strongly agree*) to self-rate and comment on their level of comfort being with, confidence interviewing, and competence working with this population in a healthcare capacity.

Analyses

IBM SPSS Statistics for Windows Version 22.0 (IBM Corp., Armonk, NY, USA) was used for quantitative analyses. A 2 (pre vs. post) x 3 (comfort, confidence, competence) repeated measures ANOVA was conducted to examine changes in students self-reported measures of comfort, confidence and competence during Phase 1 and Phase 2. Subsequent post-hoc independent *t*-tests were used to analyze the data. Mean scores for comfort, confidence, and competence were reported for post-Phase 3.

Narrative comments by participants were analyzed inductively using open-coding, where codes were attributed to fragments of sentences. The codes were then grouped together, with analysis of similarity and differences reviewed among the researchers. Final overarching themes were coupled with participant quotes to accompany the analysis in each phase.

Results

Phase 1: Early Exposure

There was a statistically significant difference pre and post early exposure, $F(1, 78) = 82$, $p < .001$, partial $n^2 = 0.55$, where the mean scores were higher after the intervention ($\mu = 3.89$, $\sigma = 0.07$) than before ($\mu = 3.23$, $\sigma = 0.08$). There was also a statistically significant difference among scores relating to comfort, confidence, and competence, $F(2, 156) = 52$, $p < .001$, partial $n^2 = 0.39$. Subsequent *t*-tests show that comfort was always rated highest ($\mu = 3.94$, $\sigma = 0.60$), followed by confidence ($\mu = 3.47$, $\sigma = 0.60$), and competence ($\mu = 3.28$, $\sigma = 0.74$). Finally, there was a significant interaction between pre and post early exposure and comfort, confidence, and competence, $F(2, 156) = 20$, $p < .001$, partial $\eta^2 = 0.06$. While post intervention scores were always greater than pre scores, the shift was greatest for competence, $t(78) = 10.6$, followed by confidence, $t(78) = 7.1$, and smallest for comfort, $t(78)= 4.9$.

Narrative comments provided by students highlighted appreciation for the value of interacting with people with lived experience with ID/DD (patient educators), the powerful messages derived from the parent stories and the importance of interprofessional teamwork. Students describe this experience as *"eye opening"* and *"providing a way to understand what it means to humanize medicine."* One student expressed a shift to a person-oriented perspective with implications for improving practice:

> "Being able to interact with patients and see the programs, understand the patient stories, and understand how we can do a better job as healthcare providers."

Students described feeling more comfortable, confident and competent, but recognize exposure alone is insufficient:

> "There's a lot to learn and we need to gain more experience through practice."

Phase 2: Clinical Skills Interviewing

There was also a significant difference between pre and post clinical skills interviewing, $F(1, 27) = 57$, $p < .001$, partial $\eta^2 = 0.55$, where the mean scores were higher after this intervention ($\mu = 3.83$, $\sigma = 0.11$) than before ($\mu = 2.94$, $\sigma = 0.12$). There were significant differences among comfort, confidence, and competence, $F(2, 54) = 52$, $p < .001$, partial $n^2 = 0.41$. Subsequent *t*-tests showed that comfort was always rated highest ($\mu = 3.92$, $\sigma = 0.53$), followed by confidence ($\mu = 3.23$, $\sigma = 0.70$), and competence ($\mu = 3.01$, $\sigma = 0.61$). Finally, there was a statistically significant interaction between pre and post clinical skills interviewing and comfort, confidence, and competence, $F(2, 54) = 8$, $p = .001$, partial $\eta^2 = 0.03$. This interaction demonstrates pre and post differences that are significant for all three measures with the greatest shift for competence, $t(27) = 7.0$ and confidence, $t(27) = 7.0$, and smaller for comfort, $t(27) = 4.6$.

Narrative comments demonstrate the importance of clinical skills with communication adaptations when interviewing patients with ID/DD. Students described this intervention as helpful with interviewing volunteer patients with mild intellectual disabilities:

> "increasing [their] ability to simplify language and communicate."

A number of students described feeling apprehensive or nervous prior to these encounters but appreciation/enjoyment following the interactions. One student shared:

> "I feel much more at ease. It sounds silly, but there is nothing to be scared or nervous about."

Another medical student explained how this experience increased confidence:

> "Getting to speak to patients was helpful and rewarding. I was able to gain more confidence in speaking with people who have DD. I learned a lot!"

Phase 3: Application

Following the third, clinical application phase of the Curriculum of Caring, after medical students had completed their clinical clerkship, 14 of the 28 students who participated volunteered to complete the post-questionnaire. Questionnaires were not provided as each student completed their individual clinical clerkship placement to preserve anonymity. Mean scores are reported for post intervention: comfort (μ = 4.07, σ = 0.62), confidence (μ = 4.07, σ = 0.83), and competence (μ = 3.57, σ = 0.85). Narratives highlighted the students' reflections on the cumulative influence of the Curriculum of Caring interventions. Some comments indicated increased comfort in speaking/interacting with people who have ID/DD and recognizing that they could *"understand them as people."* A medical student further explained the impact of this experience on future medical practice:

> We saw many children and adults with ID/DD and often many social factors complicating the picture. As a future family physician, this experience certainly impacted my ability to competently assess and acutely manage medical illness in patients with ID/DD. I feel that I now have a stepwise approach to new onset challenges in this patient population.

This description emphasizes how sequential experiences that include application of acquired learning in interprofessional settings can prepare medical students for future practices that include individuals with ID/DD. Although students generally felt more comfortable, confident, and competent, there were comments indicating more time and exposure to ID/DD healthcare across healthcare settings would be valuable.

Discussion

Undergraduate training plays a critical role in the development of professional attitudes and competencies among learners who will need to serve diverse populations and individual patients with complex needs (Kripalani et al., 2006; Long-Bellil et al., 2011; Woodard et al., 2012). Incorporation of ID/DD experiential learning provides opportunities to shift attitudes, foster cultural competencies (Huang & Malinow, 2010), and better prepare students to provide healthcare to special populations (Chew et al., 2009; Minihan et al., 2004; Woodard et al., 2012).

The Curriculum of Caring was designed to give students opportunities to learn from both patients and caregivers, develop skills interviewing people with varied cognitive and communication capabilities, and deliver relevant and timely healthcare. The inclusion of people who live with disabilities in all aspects of the curriculum is considered essential to promoting what people with disabilities say they want/need: person/family-centred care (Moores et al., 2015). Various approaches to teaching medical students about disabilities have been studied including: didactic lectures, small group interactions, and shadowing health professionals (Conill, 2008; Gosney et al., 2009; Parkin & Stein, 2001; Voelker, 2002). These studies have demonstrated positive results with development of skills, increased awareness (Conill, 2008; Gosney et al., 2009; Parkin & Stein, 2001), as well as changes in attitudes, values and beliefs around ID/DD (Parkin & Stein, 2001). The Curriculum of Caring has been distinguished by the three phase modular progression of ID/DD experiential learning throughout the undergraduate medical program. The curriculum has distinctly benefited from the involvement of patient educators in every phase.

These findings are similar to those of previous studies, (Conill, 2008; Gosney et al., 2009; Parkin & Stein, 2001; Voelker, 2002) as participants' self-reported comfort, confidence, and competence significantly increased during early exposure and clinical skills training. Following early exposure and clinical skills training, the largest shift was in competence, followed by confidence, then comfort. This smaller shift in comfort may be explained by students who started the program feeling more comfortable due to previous experiences (i.e., friends, family member, volunteering, previous work), yet not as confident or competent in interviewing or treating this population prior to clinical training. Future research could examine the impact of having previous experience with the ID/DD population and the influence of subsequent training. Narrative comments were a rich source of data for understanding the experiences and insights of students.

Limitations

Use of anonymous student questionnaires was considered efficient and feasible with limited available time. The approach built on program evaluation methods and accommodated the collection of qualitative data. However, the approach did not permit for the control of confounding variables such as previous training or the tracking of participant responses across time. A limitation of Phase 1 early exposure evaluation was blended data between medical and nursing students. Separately analyzing these two groups may have revealed differences in self-ratings of comfort, confidence and competence related to prior experience (senior nursing students clinical placements) or different narrative perspectives. A separate analysis could also have provided insight for future curriculum development specific to nursing. Another limitation was the inability to track individual medical student self-reports of comfort, confidence, competence and comments across interventions over time. Using unique identifiers could have improved the analysis, strengthened the results of this study, and provided more focused information for program refinement. Further, the use of self-assessment tools has the recognized limitation that people are generally poor assessors of their own performance or behaviour (Eva, Cunnington, Reiter, Keane, & Norman, 2004). Although students were observed by their preceptor during clinical skills and clerkship interactions, feedback was formative, and not part of the study. A final consideration is the small sample size at a regional campus, limiting generalizability of findings. Despite the limitations of the current study, it is hoped that merits of inclusion of patients/families of underserved populations in sequential training as a means of fostering cultural competencies is reinforced by the findings.

Conclusions

The Curriculum of Caring was designed as a progressive three-phase model of experiential learning to increase the capacity of future healthcare professionals to provide person/family-centred care to people affected by ID/DD. Study results show increases in comfort, confidence, and competence with a progression of experiences through medical school (early exposure to people who live with ID/DD, clinical communication skills training and opportunities for application in clinic settings.

This study adds to the literature on ID/DD curricula in medical education and supports the inclusion of patient educators in the experiential learning process. Introducing opportunities to meet with patients early in training, adapt interviews to accommodate exceptionalities, and practice with clinical teams appears to effectively shift comfort, confidence, and competence in learners and thereby increase capacity to address the needs of those with ID/DD. It is hoped that this educational initiative and preliminary study will inform the development of curricula aimed at equipping future generations of healthcare professionals with attitudes and skills that translate into the beneficial practice of person and family-centred care.

Key Messages From This Article

People with disabilities. Curriculum of Caring teaches medical students to listen to and learn from people who live with developmental disabilities. Students met with people who have lived experience with disabilities while they were in training. This helped them to feel they could do a better job when they graduate as doctors.

Professionals. Curriculum of Caring was developed to improve capacity to deliver person-centred care. Results show improved student-reported comfort, confidence, and competence in providing healthcare to this generally underserved population.

Policymakers. Healthcare education aimed at increasing capacity to care for this underserved population has the potential to improve satisfaction with healthcare services.

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