Journal on Developmental Disabilities
Le journal sur les handicaps du développement
JoDD
Volume 23, Number 3, 2018

Tell Us More – People With Developmental Disability Share Experiences to Enhance Health Care Education: An Exploratory Study

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Keywords

intellectual disability,
health care,
self-advocate,
medical education

Abstract

The prime objective of this qualitative study was to understand the health care experiences of people with developmental disability (DD) in order to inform initial and continuous training of health care professionals. Previous studies of health care experiences have not exclusively involved individuals with DD. Similar investigations involved caregivers' perceptions and have focused on specific health care settings. This study highlights the benefits of including people with developmental disability in research and as health care advisors. The study involved 22 individuals, who participated in one of seven focus groups held between February and March, 2014. Focus group participants represented a diversity of ages, as well as physical and mental health conditions. Focus group participants provided examples of both good and not so good health care experiences. They described challenges, impacts on their health, and thoughts for improving interactions. Eight dominant themes were identified: Person-Centred Health Care, Barriers to Access, Attitudes, Communication, Professionalism, Outcomes, Continuity of Care, and Inter-Professional Care. Findings have been incorporated into health care education curriculum and ongoing training activities of health professionals.

Studies in developed countries have shown that people with developmental disabilities (DD) experience poorer health, increased morbidity, earlier mortality and yet are poorly supported by health care systems (Sullivan et al., 2011). An unpublished 2004 American Academy of Developmental Medicine and Dentistry report on surveys of deans and students of American medical schools identified the need for more medical education related to people with DD (Holder, 2004). Of the deans who responded (N = 40), 53% did not feel that their graduates were competent to treat patients with neurodevelopmental disorders or intellectual disabilities. Similarly, of the graduating students who responded (N = 427), 56% felt that they were not competent to treat these patients. A 2009 publication by Holder, Waldman and Hood extended this preliminary report (Holder, Waldman, & Hood, 2009). The latter surveyed deans of American medical and dental schools and found that only 61% of deans of medical schools and 47% of deans of dental schools felt that their graduates were competent to treat patients with disabilities. Interestingly enough, they had a 55% response rate from deans of dental schools but only a 22% response rate from medical schools. Further, they found that deans were not responding because their programs were not offering any training regarding this population. There is a clear need to address not only systemic barriers to effective health care, but also the unsatisfactory experiences of people with DD as they interface with health professionals. It is well supported that compassion, empathy and person-centred approaches by health care providers are associated with improved clinical outcomes for patients (Lown, Rosen, & Martilla, 2011; Neumann et al., 2011). Person-centred care emphasizes understanding and respecting the patients' preferences, values, comfort, communication abilities and providing health care based on this understanding (Delaney, 2018). This is seen to be especially important for people whose cognitive ability and life experiences may have been quite different than peers who do not have DD. It can be assumed that significantly higher rates of abuse, exploitation and neglect for this population (Sullivan et al., 2011) would impact on this populations comfort level during health care interactions. Cognitive ability and high rates of co-occurring physical limitations (vision, hearing etc…) suggest the need for a more customized communication strategy to provide health care supports and soliciting consent to treatment (Chew et al., 2009).

Multiple studies have found that compassion, empathy and person-centred approaches to care appear to decline as medical students move through their training (Lim et al., 2013; Neumann et al., 2011; Rosenthal et al., 2011). It is recommended that DD curricula for health care learners emphasize respectful, person-centred attitudes in addition to relevant medical knowledge and skills (Ouellette-Kuntz et al., 2012).

McMaster University's Michael G DeGroote School of Medicine Niagara Regional Campus (NRC), Bethesda Services, Southern Networks Of Specialized Care (SNSC), Brock University Centre for Applied Disability Studies and Nursing, have partnered in a collaborative initiative whereby medical and nursing students experience early interactive encounters with people who have DD. A Curriculum of Caring for people with DD has been developed with experiential learning opportunities for students to learn from people with DD and their caregivers. Components of this curriculum have been used for continuing medical education training online and in person across the province of Ontario by Health Care Facilitators through the Community Networks of Specialized Care.

Focus group research on patients has become more prevalent in health care research. They have been especially helpful in exploring needs assessments, curricula development, program improvement, organization development and outcome evaluation (Leung & Savithri, 2009). Focus group research is viewed as especially advantageous to solicit information from disempowered patient groups who may feel that they have little of value to share or that any problems they experiences are a result of their own inadequacies (Kitzinger, 1995). Interestingly enough, care provider focus groups are significantly more prevalent in the research than focus groups of people with DD. A review of the literature identified a focus group study of experiences of people with DD and their care providers in U.K. hospitals (Gibbs, Brown, & Muir, 2008). While this study involved 11 individuals with DD, it also involved soliciting opinions of 14 care providers during the focus groups. This study focused on experiences within hospital settings. These tend to involve interactions with more specialized health care professionals who are involved for a shorter duration than community based providers. They tend to be more stressful for patients and focused on more acute health care issues. This study highlighted feelings of anxiety and fear, communication and behaviour problems; the practicalities of being in or attending hospitals, the role played by care providers; issues around negative comments and feelings of being treated differently. While the findings are helpful in supporting health care curricula, it was felt that additional information on lived experiences with a wider range of health care professionals (including those in longer term relationships) and different health care settings was required to enhance initial and ongoing health care education. Increasingly, medical schools have recognized the need for and benefits of involving patients with disability as teachers (Eddey, Robey, & McConnell, 1998; Minihan et al., 2004). Tracy and Iacono (2009) found a significant positive change in attitude and perception of people with DD by health care students when directly involved with them as educators.

The present focus group study advances the concept of involving people with DD as mentors and educators by soliciting perceptions of their health care experiences as well as advice to students and professionals. The focus group input enhances the Curriculum of Caring curricula for health care students and informs developmental disability health care education provided by the Southern Network of Specialized Care. The goal of this study was to inform curricula that would increase the capacity of professionals to provide competent and compassionate health care for people with DD. This article reports on findings specific to health care experiences and interactions with professionals. A separate article describing experiences with, and advice to, health care students has been published in a medical education journal (Moores, Lidster, Boyd, Kates, & Stobbe, 2015).

Methods

As described below, information to address the objective was collected from participants using a focus group format.

Ethics

This study was approved by the Hamilton Integrated Research Ethics Board and ensured that participants were informed, involved, supported and comfortable during both the recruitment phase and focus group discussions.

Study Design and Analysis

The study was qualitative in nature; it focused on responses of people with DD during semi-structured, facilitated small group interviews and written answers to questions (Appendix 1) that were distributed prior to the focus group sessions.

A pilot focus group of seven participants was conducted to test and enhance study design. It was determined that smaller group sizes were preferable for discussion purposes. Responses from the pilot focus group were not included in study findings. All focus group participants were informed that they could bring someone with them to provide personal, emotional and communication support. At the beginning of each focus group, supports were reminded of the limitations of their role. Focus groups were facilitated by two health care students and a Health Care Facilitator from the Southern Network of Specialized Care. All focus group facilitators received training from the Health Care Facilitator and the Principal Investigator on soliciting information from the participants in a way that promoted unbiased, broad-based discussion in a safe environment.

An ice breaker question (unrelated to health care) was introduced to stimulate and encourage discussion from all participants. Study participants were then asked to report on both "good" and "bad" health care experiences. They were prompted to consider interactions with all health professionals (medical doctors, nurses, dentists, paramedics, other therapists) in their responses. Focus group facilitators probed for additional context (e.g., "What made that a good/bad experience for you?"). Focus group discussions were audio recorded and then transcribed by a research team member. Audio transcripts and written responses were independently analyzed by two investigators for emerging themes and collated. Investigators translated information from the study into achievable recommendations for developmental disability medical education curriculum enhancement.

Recruitment of Participants

Study Investigators contacted all 29 government funded developmental service providers in the Hamilton Niagara area to solicit their assistance in recruiting study participants from people they support. These providers distributed a plain language recruiting package (cover letter, description of research, consents, focus group questions) to individuals involved in their residential, day, and employment programs. Interested participants submitted completed packages to a developmental service provider in their local geographic area (Haldimand, Norfolk, Niagara, Brant, and Hamilton). Focus group participants were consecutively selected and assigned to focus groups of no more than four participants. Participants were contacted by a study investigator to provide additional information about the study, confirm consent, and encourage participants to review the focus group questions in preparation for the meeting. The investigator suggested that participants write out their responses to reference during the discussion and to submit separately if they felt uncomfortable sharing with others. Participants were informed that they could invite supports to help them prepare for and communicate during the discussion.

Study Sample

The study involved seven separate focus groups of three to four participants (*N* = 22; female 17, male 5) during February and March, 2014. Study participants ranged in age from 20 to70 years, with an average age of 51 years. Participants from both urban (13 from centres over 100,000 population) and rural centres (nine from centres under 100,000 population) participated in the study. Study participants represented a wide variety of both physical and mental health diagnoses. Five study participants (23%) used mobility aids. All study participants communicated verbally in discussions. Six (27%) of the study participants were accompanied by support persons (one parent, one spouse, four direct support professionals) to provide emotional or communicative support.

Results

Study investigators identified salient themes from the analysis of participant responses. Themes were grouped under headings of (1) general health care experiences, (2) experiences with health care students, and (3) advice to health care students. This article focuses on participant's general health care experiences. Eight dominant themes were identified: Person-Centred Health Care, Barriers to Access, Attitudes, Communication, Professionalism, Outcomes, Continuity of Care, and Inter-Professional Care. These themes were universal among identified demographic characteristics (gender, age, rural/urban, physical or mental health co-morbidity).

Person-Centred Health Care

Participants clearly expressed the importance of being consulted about their health care needs and preferences. Participants described positive experiences where health professionals spent time to understand their unique health care issues and anxieties (e.g., around procedures) then jointly determined how to adapt/modify assessment and treatment.

One participant was frustrated during a hospitalization because health care providers would not give him the support he needed to manage ongoing health issues because they were not the reason he was hospitalized:

> When I was in the hospital last … they did not roll me. I'm a quadriplegic. I cannot roll myself. I get bedsores if I am not rolled. They didn't do my bowel routine either… They just didn't give a ––––. Even with rolling me, I was on the one side 6–7 hours without being rolled. They just didn't care. One nurse even said 'we don't do that here.' I was in the hospital for one reason and they did not care about the other health care support I needed in addition to that one reason. My daily care was ignored. It was left behind. This happens every time. Normal people should not have to go through this.

This participant also thought the hospital staff should have considered his inability to use the call system and placed him in a hospital room close enough for him to get attention when needed:

> If I am put in the very back of the hospital floor, far from the nursing station they can't hear me and they can't see me. I have no way of alerting them. I cannot ring the bell or push down the buzzer they leave for me … If I have a dizzy spell I have no idea where I am, let alone know how to get the buzzer or bell working.

Others described unsatisfactory experiences where modifications could have made a great deal of difference. One participant indicated that, if consulted, she would have informed hospital staff that she was left handed, and an IV on the right arm would have allowed her greater independence during her hospital stay.

Barriers to Access

Participants identified a number of significant barriers: reliance on caregivers, convincing others of illness, transportation, cost, clinic hours, emergency department busyness and wait times. Of particular interest for developmental service providers, participants identified barriers that occur prior to encounters with health care workers. One participant described a necessary medical appointment being delayed by the need to convince caregivers that her concerns were valid followed by subsequent difficulties arranging staff coverage and transportation. Several participants described the need to have someone without a disability accompany them to appointments before health care providers believed their reports of illness.

Attitudes

Participants valued friendliness, respect and honesty from health care providers. Participants commented on the importance these traits play in their level of trust with health professionals and the care they provide. One participant described her frustration with a physician not believing her:

> He tried to tell me I didn't have a seizure and I did. He kept saying he knew a lot, but he didn't … It is important that the doctor listens to your opinion on what is going on in your body … The person that had the seizure knows, you (doctor) don't … Don't tell me that I don't know my own body when I do!

Positively reinforcing the person's efforts towards good heath/dental maintenance was also appreciated by participants.

Communication

Listening, non-verbal communication (body language), manner of speech, and choice of words (plain language) are important:

> Instead of using a 30-letter word, use a five-letter word.…It is easy to explain things to her. She tries to explain things in a way I will understand. If I don't understand I can say that I don't understand and she will find another way to explain it to me.

All participants commented on the importance of effective communication. The willingness of health care providers to take the time and adapt their communication methods was identified by many as having a direct impact on health care outcomes. Participants identified less than ideal experiences where health care providers did not look at them during appointments and checked notes on the computer during interactions. "One time the doctor was talking on his headset to the computer saying 'erase that, erase that'." Several participants described positive interactions where health professionals asked if they understood and then took the time to modify their communication (plain language) so that they could be more involved in health care decisions.

Professionalism

Respectful communication, explaining/obtaining permission, punctuality, soliciting informed choice/consent, and maintaining privacy were central to successful health care experiences. Participants consistently associated these elements of professionalism with positive health care experiences. Conversely, they frequently mentioned the absence of these traits in their negative health care experiences. Many participants described their frustration with health care professionals who spoke to their supports (like they were not present), prompting one participant to wave her arm and say "Hello, I'm right here!" Participants frequently described less than ideal experiences in hospitals where other patients, visitors and professionals not directly involved in their care heard their confidential and personal information. Some reported experiences where assessment and treatments were performed without their consultation or consent. Participants also described positive scenarios where health care providers explained procedures, sought input and obtained consent. "Our doctor is awesome! Whenever we see her she will actually sit and talk to us about it… she will say that this way is the better way to go and why. She will talk about side-effects and everything."

One participant described her frustrations with health care appointments that are not kept and how it affected her health:

> [The person] was going to come and take my sugar for my diabetes. Well I waited and waited. I couldn't have my breakfast or medication. Then it came to 10:30 am and she didn't show up … Then came Friday and she still didn't show up … I was so, so mad at her for not coming those two days … It is the waiting and no one telling me when they are coming or why they are not coming that gets me angry. They can tell me when they are coming by phone.

Outcomes

Clear diagnoses, treatment success, relief from discomfort, pain management, and improved health were identified as important outcomes of health care interactions. Interestingly, several participants described positive experiences when treatments alleviated pain and discomfort; however, the attitude and behaviour of the health care professional lacked care and compassion.

Continuity of Care

Consistency and communication among health care practitioners are valued. "We are very happy with our doctor. We are never leaving her. She doesn't go into the hospital, but she does have someone to look after us there. There is good communication between the doctor and hospital." Several participants described frustration with receiving contradictory advice from different health care providers:

> The insulin was not helping. They took me off insulin and put me on metformin. Now my glucose is really, really high. They have me on another pill and I am a lot better … They blamed it on one doctor, because he put me on the insulin. I didn't like that they disagreed.

Inter-Professional Care

Involvement and collaboration from multiple health care disciplines was noted repeatedly. Participants, especially those describing multiple physical health and mental health comorbidity, identified the importance of good communication and collaboration among their health care providers for achieving satisfactory health care outcomes:

> My doctor is always doing what he can to help me. He phones around to get services for me. He gets a physiotherapist for me. He also gets nurses for me and these nurses call me. So I like my doctor.

Based on these focus group findings, enhancements to the Curriculum of Caring have been implemented.

Limitations of the Study

Investigators identified a number of potential problems related to using focus groups to solicit perceptions. There was a risk of individuals being unwilling to share experiences with supports or a group of peers (some known and some new). Facilitators provided instructions at the start of each focus group around the confidentiality of information among participants. Facilitators provided an option of providing written responses (supported if needed) for experiences that would be uncomfortable to share within a group.

There was an identified risk that coaching or comments from supports could influence participant discussion. Supports were informed prior to and at the beginning of the focus group discussion that their role was to support and not to share their own perspectives of the participants' health care experiences.

There was a potential risk that dominant opinions would stifle divergent opinions. Facilitators encouraged and validated differing perspectives. To determine whether this was a factor, investigators analyzed the verbal comments made by the participants who also submitted written comments. There was a high correlation between written and spoken comments. Investigators also analyzed transcripts within each of the focus groups and found that each group reported varied and divergent opinions about health care experiences.

There was a risk that the sample size might have been insufficient to identify a diversity of experiences. Investigators analyzed the transcripts and found that no new themes emerged (saturation) after the fourth focus group, indicating reliable results.

Obtaining a full representation of opinions of such a diverse group of people as those with DD is a challenge. Our research and findings excluded a number of important sub groups of the population including: people who have extreme difficulty communicating, people not actively being supported by a government funded developmental service provider, people faced with transportation barriers, people who could not participate due to lack of supports and people with significant emotional or behavioural issues.

Discussion

This research reinforces the invaluable benefits of directly involving people with developmental disabilities in research related to the supports and services they receive to live full and healthy lives. Focus group participants identified important attitudes and behaviours for health care providers to develop during their training and practice when interacting with patients. While these attitudes and behaviours are important in the provision of good health care to all citizens, they are essential when providing support to this population who tend to have more complex physical, medical, and mental health needs. People with lived experience can tell us more about what they need to improve the health care experience. They highlight the need for better access, caring attitudes, respectful professionalism, adapted communication, person-centred practices, good outcomes, coordinated and continuity of care. Attending to the voices of experience brings us closer to the ideals of bridging gaps in service and reducing health service inequity.

This research provided valuable personal perspectives with patient-centred recommendations to guide the enhancement of the Curriculum of Caring for People with Developmental Disability. This curriculum has been developed through a partnership of McMaster University, Michael G DeGroote School of Medicine (Niagara Region Campus) and Brock University Centre for Applied Disability Studies, Department of Nursing and Bethesda Services. Input from this focus group study has been used for curriculum refinements for broader health care training. Components of Curriculum of Caring can be accessed at CommunicateCARE.machealth.ca. They have also been incorporated into medical/health care education at the University of Toronto, Centre for Addiction and Mental Health (https://www.camh.ca/en/education/continuing-education/continuing-education-programs-and-courses/developmental-disabilities-and-mental-health-online-course) and toolkits developed by Ontario's Health Care Access Research and Developmental Disabilities (HCARDD). The HCARDD tools can be accessed at https://www.porticonetwork.ca/web/hcardd.

Key Messages From This Article

People with disabilities. You deserve good health care. Good health care is provided by professionals who listen to you and involve you in health care decisions. It is important that your voice is heard by health care providers. This study is a way for health care students and professionals to hear your voice.

Professionals. People with DD are an important source of information for evaluating and improving health care services. People with DD can contribute greatly to improving communication and clinical practices that are mutually beneficial. This study has identified key provisions, attitudes and behaviours for effective health care provision to people with DD.

Policymakers. Attitudes and behaviours of health care providers have a direct impact on health care experiences and outcomes. People with DD are at greater risk for poor health (complex medical and mental health concerns) and require extra consideration and provision to overcome barriers associated with communication and cognitive limitations. Attitudes and behaviours can be developed and enhanced during health care education and are an important component of ensuring not only good health care experiences but also outcomes for this population. People with DD should be involved in advising about provision of healthcare as well as training for health care professionals.

Acknowledgements

This research was one of a number of Curriculum of Caring related initiatives supported by a 2013–2015 Associated Medical Services (AMS) Phoenix Fellowship granted to Dr. K. Boyd (Principal Investigator). The research findings have also informed education /training initiatives of the Building Health Care Capacity Initiative (SNSC). Additional sources of support include: McMaster University Michael G DeGroote School of Medicine (Niagara Regional Campus), Brock University Nursing and Centre for Applied Disability Studies, Wilfred Laurier University (Brantford Campus), Norfolk Association for Community Living, Community Living Haldimand, Mainstream, YWCA Hamilton, Community Living Brant, Bethesda Services, and the Southern Network of Specialized Care.

Sincere thanks to focus group facilitators: Lisa Whittingham (student, Brock Centre for Applied Disability Studies), Ekta Singh and

Mariana Sanabio (students, Brock Department of Nursing), Jeanette Moores and Natalie Lidster (students, McMaster, Michael G. DeGroote School of Medicine). This study would not have been possible without the willing and active participation of the focus group members and those who supported their participation.

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Appendix 1: Focus Group Questions

We have eight main questions. We might ask you for extra information to better understand your answers.

1. Think about being outside. What is your favourite season (Fall, Winter, Spring, Summer) and why is it your favorite?
2. Think about a good health care experience. This could be with a doctor or a nurse. This could be in an office or a hospital. What made it a good experience?
3. Think about a bad health care experience. This could be with a doctor or a nurse. This could be in an office or a hospital. What made it a bad experience?
4. What would you tell students to help them be better health care workers?
5. What do you feel about health care students in the room during appointments?
6. Is there anything else you would like to tell us about your health care experiences?
7. Do you have any questions for us?
8. Is there anything else you would like to add?