Beyond equality: Providing equitable care for persons with disabilities

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ABSTRACT

Background: Almost 14% of Canadians have a disability, and older adults are most commonly affected. People living with disabilities have challenges accessing health care services, including medications and other services provided in pharmacies.

Methods: A literature review was conducted regarding disability and pharmacy services. Resources regarding accessibility were also incorporated.

Results: A number of organizations provide guidance on caring for those with disabilities. A primary

concern for these vulnerable individuals relates to being invisible or overlooked by the health care system. There are also the stresses of physical, communication and attitudinal barriers. Pharmacists may be unaware of these barriers and may actually be contributing to them. To understand their patients' accessibility needs, pharmacists can consider physical and nonphysical barriers and engage in education, advocacy and communications training to improve their patient-centred care for individuals with disabilities.

Discussion and Conclusion: Pharmacists can improve the care of individuals with disabilities by learning more about accessibility. Within the community pharmacy environment, there are physical and nonphysical interventions that pharmacists can implement to ensure that patient-centred care is prioritized. *Can Pharm J (Ott)* 2017;150:251-258

Background

There are more than 1 billion people worldwide living with a disability¹ and 3.8 million in Canada.² Multiple barriers are faced by people with disabilities when accessing health care services—these include attitudinal, communication, transportation and environmental barriers. These barriers can result in disparities in health care and compromised care.³ Some people with disabilities have been described as being invisible to pharmacists because of pharmacists' lack of knowledge or experience in addressing these barriers.⁴ However, pharmacists will encounter these patients frequently, with 43% more people with disabilities using prescription drugs compared with the nondisabled population.⁵

The World Health Organization (WHO) has identified that not only do persons with disabilities face many barriers within the health care system but they are also twice as likely to find health care providers' skills and facilities inadequate, 4 times as likely to be treated poorly by health care providers and nearly 3 times more likely to be denied health care services compared with the general population.¹ Two of the WHO-proposed solutions to improve health care for persons with disabilities are (1) to remove physical barriers to health facilities, information and equipment and (2) to train all health care workers about disability issues, including human rights and access.¹ This article attempts to use these 2 outlined solutions to enlighten Canadian pharmacists

Disability is common yet pharmacists are often not prepared to provide care for patients with disabilities. There are everyday challenges people with disabilities face with medications and pharmacies, and compiling resources can assist pharmacists to become better care providers and advocates.

Les invalidités sont courantes et pourtant les pharmaciens ne sont pas équipés pour offrir des soins aux patients handicapés. Tous les jours, les personnes handicapées rencontrent des problèmes liés aux traitements et aux pharmacies. Dresser la liste des ressources disponibles peut donc aider les pharmaciens à être de meilleurs fournisseurs et défenseurs des soins de santé.

KNOWLEDGE INTO PRACTICE

- Approximately 14% of Canada's population has a disability, and one-third of those are older than 65 years.
- People with disabilities experience many barriers to health care that create both care gaps and unmet health needs.
- People with disabilities use more prescription medications than those without disabilities, which means they access pharmacy services often.
- Understanding disability and tailoring interventions by pharmacy staff can lead to improved care for patients with disabilities.
- Pharmacists can make changes in their practices and practice settings to address physical barriers and communication challenges to improve care for patients with disabilities.

regarding barriers that persons with disabilities may be facing within their care.

Methods

To prepare this review, publications from 1946 to June 2016 were reviewed from PubMed and MEDLINE. Search terms used in each database included *pharmacy and disability*, *disability services*, *pharmacy services*, *clinical pharmacy*, *primary care*, *physical disability*, *intellectual disability*, *hearing disability*, *hearing impairment*, *visual impairment*, *mental health*, *pharmacy education*, *pharmaceutical care*, *equitable care*, *access to care* and *accessibility*. Two authors independently reviewed articles for relevance and inclusion. In addition, relevant cited articles were manually reviewed. Websites with relevant public policy surrounding disability and organizations for persons with disabilities were manually searched and reviewed. Resources from the Voice of Albertans with Disabilities were also reviewed.

Definitions/terminology

The terms *disability*, *impairment* and *handicap* are often used interchangeably. These terms have significantly different meanings, however, which is important if one wishes to begin understanding the culture of disability. The WHO, in the context of health experience, has provided definitions relating to disability (Table 1).⁶ In short, impairment is a problem relating to a structure of the body, disability is a functional limitation in performing a particular activity and handicap is a disadvantage in fulfilling a (life) role. These ideas can be linked in this manner:

Disease/disorder → Impairment → Disability → Handicap

Situations that arise are often far more complex than the above linear graphical representation. For example, a professional pianist with rheumatoid arthritis in his hands may have only a mild disability but have a severe handicap. An example of handicap without disability is a patient with bipolar disorder who is stable on medications, but bears the stigma of having an acute manic episode in the past. This highlights the importance of disability being a socially defined construct and the fact that with adaptations and removal of barriers, persons with disabilities may not experience a handicap at all. This is the concept of equitable care.

Epidemiology and impact

Approximately one-third (33.2%) of the 3.8 million Canadians with disabilities are aged 65 years and older, despite this demographic representing only 14% of the population.^{2,7} Certain disabilities, such as sensory (sight and audio) and those related to physical aspects (pain, flexibility, mobility) were more commonly reported in older individuals.

The results of the Canadian survey also showed that persons with disabilities had experienced significant disadvantages in multiple areas compared with their age-standardized counterparts.² For instance, persons with disabilities were less likely to have completed a university education (16% vs 31%), less likely to be employed (47% vs 74%) and also faced income disparities, earning as low as only 57% of the income of their age-standardized counterpart. Such disadvantages can have important financial, social and psychological implications on one's health.

Medication usage was common among persons with disabilities, with 76% reporting the use of at least 1 prescription medication per week.² However, 10% of those with disabilities reported costs of medications being a hindering factor that limited them from purchasing medications, while another 10% reported that they take their medication less frequently than prescribed because of high drug costs.²

Challenges and barriers faced by persons with disabilities

Not all disabilities are visible, meaning that many patients may be facing barriers to pharmacy services without the knowledge of pharmacy staff. A focus group of adults and proxies of persons with disabilities identified their main

TABLE 1 Terminology and examples⁶

WHO term	WHO definition	Example
Impairment	Any loss or abnormality of psychological, physiological or anatomical structure or function	A man who is blind has a vision impairment
Disability	Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being	A man who is blind has a disability as he is restricted in performing the function of seeing
Handicap	A disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex and social and cultural factors) for that individual	A man who is blind would also experience a handicap in specific environments or settings where he would be expected to drive a vehicle or read a sign or label

WHO = World Health Organization.

barriers to health care, which included insufficient time at visits to address complex health needs, inaccessible or lack of adaptable equipment and provider's communication style being inappropriate for the patient's comprehension level.⁸ Patients also identified attitudinal barriers such as "assumptions that persons with physical disabilities are cognitively impaired." The barriers that people with disabilities face with regard to access to pharmacy and health care services in general can be categorized into physical and nonphysical barriers.

Physical

Inaccessible parking areas, uneven access to buildings/pharmacies, signage, internal steps, narrow doorways and inadequate bathroom facilities account for only a small proportion of the number of physical barriers persons with disabilities face.⁹ Within the context of pharmacy products, for example, patients with limited strength or dexterity in their hand(s) may be unable to open pill bottles or product packages, administer nonoral medications such as inhalers or use testing equipment such as blood glucose monitors. Those who have vision impairment may have trouble or be unable to read prescription labels as well, which can have important ramifications on adherence, as greater reliance on memory is required.¹⁰

Lack of access to transportation is also a major inconvenience and source of discouragement in seeking health care services. Among

Canadians with disabilities, 13% reported having "some difficulty" using public and/or specialized transportation, while another 13% reported experiencing "a lot of difficulty."² Information may also be hard to access. Persons with disabilities have significantly lower rates of information and communication technology usage than those without disabilities.¹ Some may be unable to access basic products and services such as telephones or the Internet.

Nonphysical

Communication. Nonphysical aspects of health care and pharmacy access can sometimes appear more challenging, as they are less tangible. The WHO found that people with disabilities were more than twice as likely to report finding health care provider skills inadequate to meet their needs, 4 times more likely to report being treated badly and nearly 3 times more likely to report being denied care.¹ For example, a Canadian study found that patients with psychiatric conditions received less counselling on their psychiatric medications compared with patients taking medications for cardiovascular conditions, despite the majority of pharmacists believing that patients did not have all the necessary drug information from their physician or pharmacist to manage care.¹¹

Policy. Canada lacks a federal disability act. In 1990, the United States adopted the Americans with Disabilities Act (ADA),¹² a law that had 4 main purposes: (1) to provide a national

mandate to eliminate discrimination against individuals with disabilities; (2) to provide clear, strong, consistent and enforceable standards that address discrimination against persons with disabilities; (3) to ensure that the federal government has a fundamental role in the enforcement of the standards; and (4) to regulate commerce in order to combat the discrimination faced by individuals with disabilities on a daily basis. In a survey of 870 disability community leaders in the United States, two-thirds of respondents believed that the ADA has been the most significant social, cultural or legislative influence on their lives in the past 20 years. In addition, 90% of respondents believed that the quality of life for people with disabilities in communities across America has improved greatly since passage of the ADA, with some of the greatest impacts being on access to public accommodations, employment, public transportation and public awareness.¹³ Currently, Manitoba and Ontario have accessibility acts. Both aim to develop accessibility standards and thereby help remove barriers that persons with disabilities may face.^{14,15} This is an encouraging step, but federal legislation, as with the ADA, may help provide further motivation for corporations and pharmacy owners to invest in changes so that persons with disabilities receive barrier-free and equitable care.

While Canada has antidiscrimination laws through the Charter of Rights and Freedoms and the Canadian Human Rights Act, these laws may be more reactive than proactive, as with the ADA.¹⁶ The enactment of an access law or mandate may help provide the impetus and legal motivation for pharmacists to effectively provide care to individuals who have disabilities and to pharmacy corporations to provide the needed financial and informational resources to do this. Without the necessary policy and regulatory mechanisms, it rests on the individual pharmacist to take the initiative to provide additional resources and take the extra time and effort to effectively communicate with persons with disabilities. This may lead to an inconsistent level of care among pharmacy professionals.¹

Cost. Because of the complex care required, persons with disabilities are less likely to work and have drug insurance; although government drug coverage may exist for eligible patients, their adherence and access to medications

is nonetheless in jeopardy.¹⁷ The financial costs of implementing policy and the funding required for comprehensive drug coverage for individuals with disabilities is another challenge to accessibility. Some examples include, in Alberta, the Assured Income for the Severely Handicapped program, which, among other things, provides complete financial coverage for many but not all prescription medications and some over-the-counter and nutritional products for those who qualify as severely disabled. The BC Employment and Assistance for Persons with Disabilities and the Ontario Disability Support Program have made medications and other health care services much more accessible for those who have severe disabilities. However, those with a disability who do not meet the eligibility criteria for provincial programs may still have costly medication bills. Thus, the financial cost of medications remains an important barrier that precludes many people with disabilities from even contemplating accessing pharmacy services in the first place.

Responsibility and leadership: Meeting the needs of those with disabilities

Cultural context and awareness

Persons with disabilities are a unique subculture who are often forgotten in the pharmacists' discussion of cultural competence, further distancing this group from pharmacist care.¹⁷ As with any patient group, increasing knowledge, dispelling myths and learning appropriate language and communication techniques are vital steps. The barriers created by our lack of awareness and knowledge can be easy to remove. Seeing persons with disabilities as persons first, without preconceived views or assumptions of their limitations based on their disability, may be the first step to providing equitable care.

In addition to awareness of the culture and needs, there are physiologic differences that may influence medication decisions. For example, because of metabolic differences and central nervous system conditions that may exist, persons with developmental disabilities are likely to react differently to medications.¹⁸

Advocacy

To advocate for patients with disabilities, pharmacists must first know what barriers their

patients are experiencing. While physical and nonphysical barriers are already described in general, it is important to involve patients in the discussion and the solutions that best apply. Organizations and advocacy bodies help to provide insight into challenges and barriers faced by those they represent. For example, the Voice of Albertans with Disabilities, which represents people with all forms of disability, has published a thorough document to help guide health care providers on the disparities experienced, titled “Barrier-Free Health and Medical Services in Alberta.”³ With the Blueprint for Pharmacy advocating for “optimal drug therapy outcomes for Canadians through patient-centred care,” Canadian pharmacists should be taking these barriers into account to provide patient-centred care and advance pharmacy practice.¹⁹

Changes in pharmacy: Breaking down barriers

Patient-focused changes

Mobility. For persons with mobility impairments, pharmacists should be wary of items such as promotional cardboard stands, stock boxes or stepladders that may litter pharmacy aisles. Removing such items will help to minimize tripping hazards, decrease the number of obstacles a person may have to navigate and also help to increase the visibility of more products. In addition, any loose floor mats, which may also have the potential to create a tripping hazard, should be removed.

Within the pharmacy, being mindful of refill timing for persons with mobility disabilities and/or transportation schedules can make a significant impact. Aiming to have all medications synced to be refilled concomitantly will reduce the number of trips a patient may have to arrange. Home delivery of medications exists as an alternative but removes the opportunity for pharmacist interaction and in-person counselling.

Dexterity. For persons with limited dexterity of the hands, in addition to dispensing medication with easy-open caps, consider dispensing medication in vials that are a larger size than needed, as the increased circumference of the vial may make it easier to grip and less prone to spilling. In situations where a patient may lack hand strength and sufficient hand-eye

MISE EN PRATIQUE DES CONNAISSANCES

- Près de 14 % des Canadiens souffrent d’une invalidité et un tiers d’entre eux est âgé de plus de 65 ans.
- Les personnes handicapées rencontrent de nombreux obstacles en matière de soins de santé ce qui suscite à la fois un manque de soins et des besoins non satisfaits.
- Les personnes ayant des invalidités consomment plus de médicaments d’ordonnance que les personnes qui n’en ont pas, ce qui signifie qu’ils utilisent souvent les services des pharmacies.
- La compréhension des invalidités et l’adaptation des interventions par le personnel de la pharmacie peuvent permettre d’améliorer les soins de santé pour les personnes handicapées.
- Les pharmaciens peuvent adapter leurs fonctions et leur environnement professionnel pour contourner les obstacles matériels et les problèmes de communication afin d’améliorer les soins offerts aux personnes handicapées.

coordination to use devices such as inhalers, offer the option to use the inhaler with a holding chamber or consider devices used for individuals with arthritis that allow for larger grip (e.g., devices to help instill eyedrops).

Visual communication. Information in a pharmacy is often provided in small print and compressed to fit into compact spaces. Certain features such as small print size with all capitalized letters on vial labels and monochrome text or compressed line spacing on patient leaflets make it especially difficult to read for those with visual impairments.^{20,21}

Vial labels can be configured via label settings within the pharmacy computer software to maximize visibility and help those who face reading challenges. It is recommended that fonts be bolded to help increase legibility, and selected information or keywords may be emphasized by bolding, using a contrasting color or increase in font size.^{20,21} In addition, avoid using tape with a glossy surface, such as packing tape, to laminate vial labels. The glossy surface can reflect light and cause glare, which may make vial labels even harder to read.^{20,21} The font should be between 12 and 18 point and may be easier to read if a contrasting colour is used, such as a yellow, behind a black font instead of white.²¹ For patient information or monographs, it may be beneficial to consult external sources such as Lexicomp, which provides information that can be printed in font sizes of up to 18 point. In terms of prescription medication labelling,

TABLE 2 Terminology and use of language²³

Inappropriate choice of words	Appropriate choice of words
(The) handicapped, invalid	Person with a disability
Person who has trouble _____	Person who needs _____
Person suffering from, stricken with, afflicted by, victims of	Person with a disability
Normal (person, people, etc.)	Person without a disability
(The) blind, visually impaired	Person who is blind, person with visual impairment
(The) hard of hearing, hearing impaired	Person who is hard of hearing, person with hearing impairment
(The) crippled, lame	Person with a disability, person with mobility impairment, person who has a spinal cord injury
Mentally retarded, feeble minded, retarded, simple, etc.	Person with an intellectual disability

Excerpt from Employment and Social Development Canada's Table of Appropriate Words.

the Canadian Public Health Association recommends the use of sans serif typefaces (Helvetica, Univers or Arial) when font size is less than 10.²²

For any patient with severe vision impairment that interferes with medication administration and adherence, blister packaging of medications is an alternative that reduces the need to rely on memory and also ensures correct dosing of medications.

Pharmacist-focused changes

Education. Many barriers to care may exist because of the lack of disability awareness training that pharmacy teams have undergone. Cultural competency components in pharmacy education often contain either little or no mention of disability issues.¹⁷ Learning about disability through a cultural competency framework can be effective in teaching pharmacy students the general approaches and communication models for working with a specific population and can help achieve equal health outcomes between persons with and without disabilities.¹⁷ Similarly, the WHO recommends integrating disability education into education given to health care providers. One method involves the incorporation of people with disabilities as providers of education, helping improve service provider attitudes and knowledge and empowering people with disabilities.¹ Websites such as selfdirection.

org offer online disability awareness training, and disability advocacy groups, such as the Voice of Albertans with Disabilities, offer free disability awareness training. These training sessions teach participants to see a person's abilities rather than their disabilities and to reduce misconceptions about disability. Use of appropriate language surrounding disability is also important in providing care, as it demonstrates a level of understanding and knowledge (Table 2).²³ For example, stating that someone has a disability instead of saying they are disabled allows the person to be put first and not labelled by their disability. Person-first language that recognizes that someone is more than their disability should be the standard.

Communication tips. Usually used for persons who may not be able to read or comprehend English, pictograms are a helpful tool in providing directions for using medications. Pictograms provide the direction in pictures rather than text so that they are more widely understood and are not limited to a language. Pictograms can also be helpful for persons who may have difficulty reading the fine print that is often on pharmacy labels or for those with cognitive impairments. The International Pharmaceutical Federation has easy-to-use software for creation of pictograms at www.fip.org/pictograms.

Amplified communication devices or a device with volume control, such as a hearing loop, may be beneficial to persons who are hard of hearing. TTY devices and other telecommunication techniques allow patients who are hard of hearing to use the telephone to send a text message that will be read by an operator. Relay Phone systems, such as the one offered by Bell Canada, do not charge for local calls, and all operators are bound to a code of ethics to ensure confidentiality.

Ensuring good lighting, proper enunciation and eye contact can be helpful for persons who speech read while communicating. Thought should also be given to the use of mainstream technologies when communicating with the deaf or hard of hearing. Although pharmacists should be cognizant of laws involving transmission of health information, cellular devices and smartphones are widely used by persons with disabilities for their SMS, text and accessibility features.²⁴

Other. When serving persons with disabilities, pharmacists should communicate primarily with the person, rather than focusing on the caregiver. Other pharmacy services, such as compliance packaging, prescription delivery and calling on prescriptions when ready may also be offered to persons with disabilities. A shared decision-making approach and partnering with the person in their care will help to determine what services will be of

benefit. Depending on provincial coverage and pharmacy reimbursement programs, evidence also exists for medication reviews and education for persons with developmental disabilities to increase compliance and improve health outcomes.²⁵

Conclusion

The number of Canadians who have a disability is very high, and they have greater medication and health care needs than the population without disabilities. This means that pharmacists and pharmacy staff will interact frequently with those with disabilities. Persons with disabilities often receive a lower standard of care in addition to facing multiple barriers to access health care. Pharmacists can address this inequity through increasing awareness and education, communicating with the correct terminology and making physical and process changes within the pharmacy that better serve this vulnerable population. Pharmacists can also engage in advocacy at the patient level and support local, provincial and national efforts for accessibility. Through adaptability and person-centred care, pharmacists have the ability to reduce barriers faced by people with disabilities. Proactively starting a conversation and individualizing our approach to disability are simple interventions that allow us to learn from people with disabilities and enable equitable care. ■

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