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Equity for All: Providing Accessible Healthcare for Patients Living with Disabilities

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Public Health in Pharmacy Practice: A Casebook

PUBLIC HEALTH IN PHARMACY PRACTICE: A CASEBOOK

2nd Edition

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OCHS, AND LINDSAY WADDINGTON



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3I.

EQUITY FOR ALL: PROVIDING ACCESSIBLE HEALTHCARE FOR PATIENTS LIVING WITH DISABILITIES

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Topic Area

Disabilities

Learning Objectives

At the end of this activity, students will be able to:

- Identify relevant resources to assist patients living with disabilities
- Recommend appropriate patient-specific resources to minimize barriers to health
- Identify strategies to enhance the healthcare experience of patients living with dis-

abilities

- Describe the policies that currently exist to enhance care for patients living with disabilities

Introduction

According to the Americans with Disabilities Act Amendments Act (ADAAA), disability is defined as “an impairment that substantially limits one or more major life activities, a record of such an impairment, or being regarded as having such an impairment.”¹ The World Health Organization (WHO) and the International Classification of Functioning, Disability, and Health (ICF), which provides a framework for the measurement of functioning and disability, defines disability as an “umbrella term, covering impairments, activity limitations, and participation restrictions.”² Approximately 26% or 61 million adults in the United States currently live with a disability.³ For some patients, especially those with disabilities, obtaining access to healthcare services as well as communicating with healthcare professionals can be an extremely challenging experience. A lack of proper access to healthcare services and/or ineffective health communication may lead to poor patient understanding of their health and current/potential treatment options, low quality of life, and negative health-related outcomes.

The term “disability” encompasses diverse categories of impairments, activity limitations, and restrictions which includes visual impairment, hearing impairment, motor impairment, cognitive/learning impairment, and speech disabilities or difficulties. While each of these categories are defined differently by various agencies, generally recognized definitions/descriptions can be found within the Individuals with Disabilities Education Act (IDEA). According to IDEA, an individual has a visual impairment if they experience vision loss that cannot be corrected. Hearing impairments, on the other hand, can be permanent or fluctuating, with deafness specifically defined as having a severe form of impairment in the ability to process linguistic information through hearing. Motor impairment involves the partial or complete loss of function of a body part, while cognitive or learning impairment is defined as “a disorder in one or more psychological processes that are important for understanding and using language”. Finally, speech or language impairment is defined as a communication disorder and includes stuttering and voice impairment, for example.⁴ However, this is by no means a comprehensive list of all of the disabilities that individuals experience, and they may not always be readily apparent to others. Indeed, there are many individuals who have less obvious disabilities that are “hidden” or “invis-

ible.” Finding one standard definition of a hidden/invisible disability is a challenge and finding resources for these patients can be more challenging. Consequently, there is much advocacy for people with this type of disability.

Regardless of the type, individuals with disabilities may encounter their own unique set of barriers that can hinder healthcare access. It is important to see each patient as an individual and tailor care to each person’s specific preferences and needs. It is vital that healthcare professionals obtain the requisite education and knowledge to provide appropriate health services to individuals with disabilities. Improving healthcare professionals’ competence and skills in providing care to and communicating with patients with disabilities will increase patients’ knowledge of their health care and associated treatments,⁵ ensure safer medication use, and optimize patient health-related outcomes.⁶

Case

Scenario

You are a pharmacist in a federally qualified health center.

CC: “My wife is here for an appointment.”

Patient: MC is a 63-year-old female (64 in, 73 kg) who presents with her husband for an appointment. The patient is smiling and engaged but turns to her husband when you begin to ask questions. You see that the patient is communicating with her husband with sign language.

HPI: Per the medical record, MC was started on insulin about one month ago due to uncontrolled diabetes after about five years of oral medications. You notice that she has not started the insulin because she brings all her medications to the appointment and the insulin and supplies are not included.

PMH: T2DM, HTN, hyperlipidemia, allergic rhinitis

FH:

- Married with three adult children
- Father: deceased (age 72 from MI)

- Mother: alive; HTN, hyperlipidemia

SH:

- Denies ever having used tobacco
- Denies illicit drug use
- Husband is a current smoker (20 pack-year history)

Medications:

- Basaglar 10 units subcutaneously daily
- Metformin 1000 mg BID
- Glipizide 10 mg BID
- Lisinopril 40 mg daily
- Atorvastatin 40 mg daily
- Aspirin 81 mg daily
- Cetirizine 10 mg daily

Allergies: NKDA**Vitals:**

- BP 128/79 mmHg
- HR 72 bpm
- RR 18/min
- Temp 98.6°F
- Pulse ox 97% on RA

Labs:

Parameter	Value	Parameter	Value
Na	138 mEq/L	Ca	9.7 mg/L
K	4.6 mEq/L	Mg	3.7 mg/L
Cl	105 mEq/L	HgbA1c	9.5%
SCr	0.9 mg/dL	Glu (random)	216 mg/dL
BUN	16 mg/dL		

Surgical history: N/A

SDH: The patient is currently uninsured. She works part-time and has a family income of approximately \$1800 per month.

Additional context: MC is deaf and communicates with her husband using sign language. The patient's husband says that they both need some help in accessing a new medication. After you develop some rapport with the couple, while trying to understand the challenges to medication access and working through some paperwork, the patient's husband states that he is unable to read.

Case Questions

1. What concepts or techniques can be used when communicating with MC to ensure her complete understanding?
2. How can you approach the topic of how the patient prefers to communicate?
3. What are some barriers to health that MC has?
4. What resources can you recommend to MC to help her navigate barriers to care?
5. What are strategies can you implement to improve MC's healthcare experience?
6. How can your healthcare organization improve the way that they provide care for patients with disabilities? What policies/laws exist to assist individuals with disabilities?

Author Commentary

The National Center for Health Statistics reports that approximately 37.6 million adults have some level of hearing loss/impairment.⁷ Hearing loss/impairments can present barriers to effective healthcare delivery by pharmacists. Research has shown that pharmacists may not be not fully prepared to understand or serve patients who are deaf or hard of hearing.⁶ Deaf/hard of hearing patients have reported being uncomfortable during interactions with pharmacists, along with fear, anxiety and mistrust toward the overall healthcare system.⁸ Pharmacists and student pharmacists can improve patient interactions with individuals who are deaf/hard of hearing by utilizing effective communication practices as a whole, like using direct eye contact and speaking to the patient as much as possible, not the caregiver or interpreter. Helpful resources like the

guide on communicating with hard of hearing/deaf patients developed by Hearing Loss Association of America can inform pharmacists about things they should do when communicating with patients. Training that focuses on providing care to patients with hearing loss or impairment and other disabilities can and should be incorporated throughout the pharmacy curriculum.

Insufficient communication between pharmacists and deaf/hard of hearing patients will hinder the establishment of rapport.⁹ A strained pharmacist-patient relationship can lead to the widening of healthcare disparities and exacerbation of negative treatment outcomes or may result in lack of knowledge of important health issues and/or avoidance of care altogether.^{8,9} Therefore, reducing or eliminating the barriers to healthcare access for deaf/hard of hearing patients is crucial for successful and effective healthcare interactions.

Patient Approaches and Opportunities

To effectively care for a patient with a disability, it is imperative that the healthcare professional first ascertain the patient's preferred mode of communicating. Then, to the extent possible, the healthcare professional should honor the patient's request to communicate in that mode for the duration of the interaction. Patients may prefer to use pen and paper, lip read, visual demonstrations (when applicable), a communication app or other type of assistive technology to communicate. Hence, there are a variety of different modes of communication for patients with disabilities, and identifying and using the one that the patient prefers will help provide a more successful patient encounter. **Table 1** discusses additional barriers to health for patients with disabilities and strategies that can be used to enhance patient access. Some tips for developing effective health communication materials for patients include: (1) use plain language; (2) limit information to three to five key points; (3) be specific and concrete; (4) use visuals; (5) include a summary that repeats the key points; and (6) use positive, hopeful, and empowering language.

Table 1. Barriers to health and strategies to enhance access¹⁰⁻¹²

Category	Example barriers to health	Strategies to enhancing access
General recommendations	Difficulties with communicating with health-care providers and personnel	<p>Talk with persons with disabilities in the same way and with a normal tone of voice (not shouting) as you would talk with anyone else</p> <p>Take steps to ensure that effective communication strategies are used; this includes sitting or standing at eye level with the patient and making appropriate eye contact</p> <p>Talk to people with disabilities as adults <i>and</i> talk with them directly rather than to an accompanying person</p> <p>Ask the person with a disability if assistance is needed and do not assume that help is needed until you ask</p> <p>Use “people-first language”: refer to “a person with a disability” rather than “the disabled person” or “the disabled”</p> <p>Never pet or otherwise distract a canine companion or service animal unless the owner has given you explicit permission to do so</p>
Visual impairment	<p>Trouble or inability to read prescription labels</p> <p>Difficulties with accessing information or communication technology</p>	<p>Identify yourself when you approach a person who has low vision or blindness</p> <p>Introduce anyone with you to a person with vision loss</p> <p>Speak the person’s name or touch the person’s arm lightly when you speak so that s/he knows to whom you are speaking before you begin</p> <p>Face the person and speak directly to him/her; use a normal tone of voice (avoid shouting)</p> <p>Explain when you are leaving the environment</p> <p>Increase the visibility of prescription labels (e.g., font size 12, sans serif, bolded, avoiding glossy tape, highlighting key words)</p> <p>Provide ample space between words</p> <p>Use yellow paper with black ink for contrast</p> <p>Use blister packaging</p>

Category	Example barriers to health	Strategies to enhancing access
Hearing impairment	<p>Difficulties with communicating with health-care providers and personnel</p> <p>Lack of interpreters available to facilitate communication</p>	<p>Ask the person who is hard of hearing, deaf, or deaf-blind how s/he prefers to communicate</p> <p>Eliminate or minimize background noise and distractions</p> <p>Use amplified communication devices, devices with volume control, TTY devices</p> <p>If you are speaking through a sign language interpreter, pause occasionally to allow the interpreter time to translate completely and accurately</p> <p>Talk directly to the person who is assisted by a sign language interpreter, not to the interpreter, even if the person is looking at the interpreter and does not make eye contact with you</p> <p>Before you start to speak, get the attention of the person you are addressing using visual (wave) or tactile signals (light touch)</p> <p>Speak without exaggerating your words and do not raise your voice, unless you are specifically requested to do so (do not shout)</p>
Motor impairment	<p>Difficulties with accessing transportation and navigating through physical environments</p> <p>Difficulties with opening pill bottles or packaging, using nonoral formulations, using testing supplies</p>	<p>Provide wheelchair-accessible pharmacy consultation areas</p> <p>Do not push or move a person's wheelchair or grab a person's arm to provide assistance without asking first</p> <p>Eliminate obstacles to the pharmacy register (e.g., promotional cardboard stands, stock boxes, stepladders)</p> <p>Sync medication fills to reduce number of trips to the pharmacy</p> <p>Dispense in easy-open caps, use larger vial sizes</p> <p>Use devices (e.g., spacers for inhalers, devices to help instill eye drops)</p> <p>When speaking to a person seated using a wheelchair/scooter, sit so that you and the person are at the same eye level</p>

Category	Example barriers to health	Strategies to enhancing access
Cognitive/learning impairment	<p>Having a disability is often associated with stigma</p> <p>May require additional time to process questions and formulate responses</p> <p>May not recall long questions</p> <p>May have difficulties in requesting help or asking questions</p> <p>May have difficulties with explaining health conditions or locating pain</p> <p>Important medical information may be missed</p>	<p>Adjust your method of communication as necessary depending on the individual's responses to you</p> <p>Use simple, direct sentences or supplementary visual forms of communication, such as gestures, diagrams, or demonstrations, if indicated</p> <p>Avoid sensory overload by providing information gradually and clearly</p> <p>Use concrete, specific language and avoid abstract language and simplistic wording</p> <p>When possible, use words that relate to things you both can see</p> <p>Be prepared to repeat the same information more than once in different ways</p> <p>Give exact instructions. For example, "You will see the pharmacist at 10:30," rather than "Come back to see the pharmacist in 15 minutes"</p> <p>When asking questions, phrase them without suggesting desired or preferred responses as some people with intellectual, cognitive, or developmental disabilities may tell you what they think you want to hear</p> <p>Recognize that the person may need to have directions repeated and may take notes to help remember directions or the sequence of tasks; they may also benefit from watching a task demonstrated</p> <p>Use/discuss medication adherence tools (e.g., pillboxes, adherence packaging, calendars, phone alarms)</p> <p>Simplify medication regimen(s) when possible (e.g., once daily dosing, extended-release formulations)</p> <p>Review medication regimens to avoid polypharmacy</p> <p>Use pictograms when explaining directions</p> <p>Treat adults with intellectual, cognitive, or developmental disabilities as adults</p>
Speech disabilities/difficulties	<p>May have difficulties explaining health conditions/verbalizing concerns</p>	<p>Talk to people with speech disabilities as you would talk to anyone else; use your regular tone of voice (without shouting)</p>

Category	Example barriers to health	Strategies to enhancing access
		<p>Be patient because it may take the person extra time to communicate; do not speak for the person or complete the person's sentences</p> <p>Give the person your undivided attention and eliminate background noise and distractions</p> <p>Repeat what you understand and note the person's reactions, which can indicate if you have understood correctly</p> <p>Do not pretend to understand if you do not – tell the person you do not understand what s/he has said and ask the person to repeat the message, spell it, tell it in a different way, or write it down (use hand gestures and notes)</p> <p>To obtain information quickly, ask short questions that require brief answers or a head nod; avoid insulting the person's intelligence with oversimplification</p>

Important Resources

Related chapters of interest:

- [Communicating health information: hidden barriers and practical approaches](#)
- [More than just diet and exercise: social determinants of health and well-being](#)
- [Saying what you mean doesn't always mean what you say: cross-cultural communication](#)
- [Let your pharmacist be your guide: navigating barriers to pharmaceutical access](#)
- [Expanding the pharmacists' role: assessing mental health and suicide](#)

External resources:

- Websites:
 - Center for Medicare and Medicaid Services. Improving access to care for people with disabilities. <https://www.cms.gov/About-CMS/Agency-Information/OMH/resource-center/hcps-and-researchers/Improving-Access-to-Care-for-People-with-Disabilities>

- Centers for Disease Control and Prevention. Disability and health information for health care providers. <https://www.cdc.gov/ncbddd/disabilityandhealth/hcp.html>
 - Centers for Disease Control and Prevention. Disability and health resources for facilitating inclusion and overcoming barriers. <https://www.cdc.gov/ncbddd/disabilityandhealth/disability-resources.html>
 - Centers for Disease Control and Prevention. Disability and health emergency preparedness tools and resources. <https://www.cdc.gov/ncbddd/disabilityandhealth/emergency-tools.html>
 - National League for Nursing. Communicating with people with disabilities. <http://www.nln.org/professional-development-programs/teaching-resources/ace-d/additional-resources/communicating-with-people-with-disabilities>
 - *Healthy People 2020*. Disability and health. <https://www.healthypeople.gov/2020/topics-objectives/topic/disability-and-health>
 - United Nations Development Programme. Universal design in health care institutions manual. https://issuu.com/undp37/docs/manual_ud.in.health-care_eng
 - The Center for Universal Design. Environments and products for all people. <https://projects.ncsu.edu/ncsu/design/cud/>
- Journal articles:
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- Other:
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 - University of Delaware Center for Disabilities Studies. Effective communication for health care providers: a guide to caring for people with disabilities. <http://www.cds.udel.edu/wp-content/uploads/2017/02/effective-communication.pdf>
 - Alliance for Disability in Health Care Education. Core competencies on disability for health care education. <https://nisonger.osu.edu/wp-content/uploads/2019/08/post-consensus-Core-Competencies-on-Disability.8.5.19.pdf>

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Glossary and Abbreviations

- [Glossary](#)
- [Abbreviations](#)