BEYOND LIMITS

CARING FOR PATIENTS WITH DISABILITIES

Hospital for Special Care's pharmacy consults directly with patients in the inpatient care setting. **Seated, left to right:** Kevin Gatland, PharmD, director of pharmacy; and Alfred C., a patient rehabilitating following spinal cord injury. **Standing, left to right:** Kevin Awugah, PharmD, clinical pharmacist; and Nicole Bassett, PharmD, pharmacy clinical coordinator

Opposite page: Bassett provides medication education and support to Al C., a patient with a spinal cord injury, during an outpatient physical therapy visit.

The expectations for patients and pharmacists are a little different at the Hospital for Special Care in New Britain, CT. Most patients are not expecting to have a pharmacist visit them," said Kevin Awugah, PharmD, a clinical pharmacist covering the medical rehabilitation unit and neurobehavioral units. Patients certainly don't think a pharmacist will come read to them, either—but that happens on occasion when pharmacists and other hospital staff volunteer to read books to pediatric patients on weekends.

OLD-FASHIONED COMMUNICATION

The patient populations at Hospital for Special Care are unique, as is the care given to each individual. The free-standing, 228-bed, long-term acute care hospital for adults and pediatric patients provides treatment and rehabilitation in pulmonary care, acquired brain injury, neuromuscular disorders, spinal cord injury, complex pediatrics, autism spectrum disorder, and much more.

"We have more time to get to know our patients than in the time frame of a typical acute care setting," said Nicole Bassett, PharmD, pharmacy clinical coordinator at the hospital. "We witness them rebuilding their lives, and we want them to be able to go home to an enriching life."

The level of complexity for each patient is much higher, even when it concerns their medications. Getting patients and their family or caregivers comfortable with a medication regimen at discharge after weeks or even months in the hospital involves a good deal of interaction.

Kevin Gatland, PharmD, director of pharmacy, said pharmacists often receive feedback from patients and their families as well as providers about how much they appreciate the education a pharmacist provides. It feels novel to have a pharmacist take the time to sit down with them and explain what they need to know about their medications, including how to take them.

Feeling comfortable with a new medication regimen after a prolonged hospital stay can also be anxiety-provoking for many patients and their caregivers or family—another reason patient education is important.

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While most pharmacists, especially those in the community setting, are not accustomed to providing care for patients with disabilities, Bassett said the overarching message is simple and can translate to any setting.

"Arranging transportation or automatic refills is certainly important, but a lot of it is good old-fashioned communication—that's going to be most helpful," she said.

Unlike patients in an acute care emergency setting, patients admitted to Hospital for Special Care are in a stabilized setting for an extended time period. The eight pharmacists on staff work closely with patients and their families or caregivers and other health care providers. Rounding with the multidisciplinary team is a normal part of a pharmacist's day.

Providers at the hospital rely on pharmacists for answers and opinions. When providing care for patients with autism spectrum disorder and their families, for example, pharmacists and physicians work closely together to make sure a patient is on the right medications and the right dose. It's often the case that patients with autism are overmedicated. Patient monitoring is normally involved, too.

"We haven't done our job if the family isn't equipped at discharge," said Bassett.

DON'T MAKE ASSUMPTIONS

W. Thomas Smith, PharmD, JD, dean of pharmacy programs at Manchester University in Indiana, has lived with a physical disability himself. In the classroom, he encourages students to talk about cultural sensitivity more

broadly to extend beyond race and ethnicity.

"Younger pharmacists have the opportunity to engage in cultural sensitivity education in the newer curriculum, but in thinking about my generation and older, that wasn't part of the everyday vernacular," he said.

Still, many pharmacists—young and old—don't consider accommodating a person with a disability until one patient opens up their eyes.

Awugah works closely with patients like Alfred C. while they receive intensive rehabilitation services at the hospital's Medical Rehabilitation Unit.

Jeffrey Mazzamurro, PharmD, was finishing up pharmacy school in Massachusetts when a motor vehicle incident left him with limited movement throughout most of his body. He now uses a wheelchair.

"Don't make assumptions," said Mazzamurro. Because he has a physical disability, he said people tend to think he has an intellectual disability, too. Smith said he has gone into a pharmacy and the pharmacist or pharmacy technician has spoken to him at the top of their lungs or very slowly.

"That stigma comes with someone with a physical disability, unfortunately, but don't assume that," said Smith. "We tend to leap to conclusions, oftentimes without all the information we need."

When communicating with patients with disabilities, Smith said, it's important for pharmacists to go back to their training, and recall how they were taught to counsel patients.

Mazzamurro added that part of a health care provider's job is to listen to the patient, which means asking the right questions. "Focusing on the patient's quality of life is important," Mazzamurro said.

The pharmacist who fills his prescriptions, for instance, needs to understand he has limited mobility with his fingers and arms.

"I need screw caps, not childproof caps," said Mazzamurro.

While the Americans with Disabilities Act (ADA) helps to ensure that patients with disabilities don't have barriers to receiving their care, Smith said pharmacists still need to be aware of potential structural limitations inside and outside the pharmacy. For example, are there ample accessible handicap parking spaces, and are the store aisles wide enough and not littered with boxes so they can accommodate a wheelchair or walker?

"I think of the ADA as more the floor, not the ceiling," said Smith. "On paper, a pharmacy might appear accessible, but oftentimes there's a flaw in the design. You go up to the pharmacy counter, and it's 5 feet off the ground, making it difficult for someone in a wheelchair to be counseled."

Even if a pharmacy has sufficient accessible parking spots and wide aisles, said Smith, other important services, like the pharmacy's website or refill line, might not be accessible to a person with a disability.

"That goes beyond ADA, but in keeping with the spirit of inclusivity and helping persons with disabilities avail themselves of all the support others get, it takes stepping back. It seems simple, but a pharmacist usually doesn't think about what to do in such an encounter until they have to," said Smith.

UNDERSTANDING INTELLECTUAL AND OTHER INVISIBLE DISABILITIES

According to CDC, one of five U.S. adults has a disability. Many of these individuals have an intellectual disability, which are often invisible.

Steven Erickson, PharmD, an associate professor at the University of Michigan's College of Pharmacy, has built up a body of research on effective medication use for individuals with intellectual and developmental disabilities.

One recent study compared hospitalization rates for people with and without intellectual and developmental disabilities. The findings, published in the *American Journal on Intellectual and*

Developmental Disabilities in January 2020, demonstrated that compared with the general adult population, a significantly greater portion of hospitalizations for adults with an intellectual or developmental disability were associated with adverse medication events.

"The medication management process for all is first going to the doctor and interacting with the prescriber to get a prescription," said Erickson. "Right there, we find potential problems for someone who has cognitive impairment. [For the prescriber,] there's the question of time and communicating well with the patient as well as the support person. Lots of mistakes can happen at this step. For example, maybe the patient can't [properly explain] the problem, and issues go undiagnosed."

Next, there can be barriers for the patient in getting to the pharmacy to pick up the prescription and then barriers for the pharmacist in properly educating the patient and their caregiver about the medication.

"Support people are very important, so it's often a question of their level of health literacy," said Erickson.

Over the past 4 years, Erickson has conducted research specifically examining the caregiver's perspective in medication management for those with intellectual or developmental disabilities.

"You go up to the pharmacy counter, and it's 5 feet off the ground, making it difficult for someone in a wheelchair to be counseled."

"Between what's already in the literature and my work, I think we are getting a better handle on it, but we are not all the way there," he said.

Throughout his research, Erickson said caregivers have consistently expressed the value they see in a pharmacist's accessibility and expertise.

Left to right: Bassett; Samantha Sowik, RT, respiratory therapist; and Gatland work together as part of the multidisciplinary patient care team.

Resources

- Vanderbilt University Kennedy Center, "Health care for adults with intellectual and developmental disabilities"(https://iddtoolkit.vkcsites.org/) and tip sheet (https://vkc.mc.vanderbilt.edu/assets/files/tipsheets/idtips.pdf)
- Free videos on proper use of medications for the deaf community, covering topics such as injecting medications subcutaneously, using inhalers, and applying fentanyl patches (http://rxtips.medsoncue.com/asl)
- FAQs on deaf and hard of hearing community and culture (https://www.nad.org/resources/american-sign-language/community-and-culture-frequently-asked-questions/)

"Caregivers are vested in doing the right thing, but sometimes these folks don't have much education themselves, so they value the help of someone like a pharmacist who is accessible," said Erickson.

A good first step for pharmacists is to become aware of common developmental and intellectual disabilities and the health care needs and comorbidities that accompany them, he said.

"I also think it's important to work on communication skills and one's ability to interact with a person who has a disability," said Erickson. Following up and monitoring the patient—even periodically reaching out—comes along with this.

In considering the communication style, pharmacists should think about how to ask questions and how to best educate.

"Most patient education material is not written for mild cognitive impairment, so pictures are important if these kinds of materials can be developed," said Erickson. Pharmacists should never overlook the opportunity to educate a patient with an intellectual disability, he said, because pharmacists are the last check on the patient's medication and can tell the difference between something as simple as needing to take the red pill and not the blue one.

CARING FOR BLIND AND DEAF PATIENTS

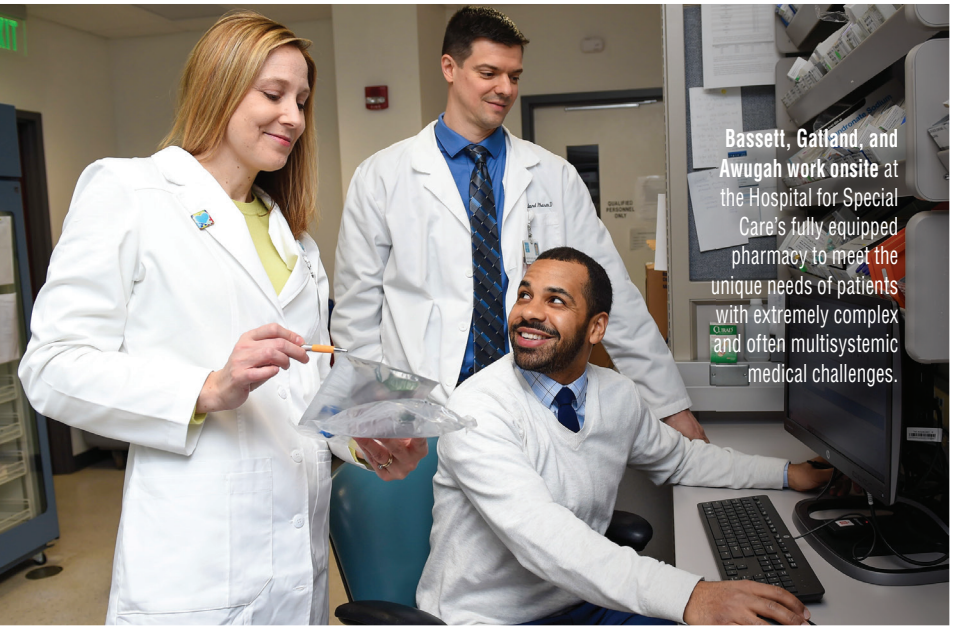
When it comes to caring for deaf and hard of hearing patients, pharmacists—both in the community and in hospitals—need to educate themselves on how to communicate most effectively.

Steven Kramer, a student pharmacist at St. Louis College of Pharmacy in St. Louis, MO, is passionate about serving the Deaf community. At his college of pharmacy, he developed an American Sign Language (ASL) club and regularly organizes health fairs specifically targeted to the Deaf community in St. Louis.

At a recent town hall meeting with people with disabilities, Kramer said that in general, Deaf patients reported

that community pharmacists and technicians do a good job counseling them about their medications. "They usually make sure to stop whatever they were doing to either write down information or speak clearly to them or a loved one about the new medication and how to take it," he said.

But the hospital was a different story. He said that in the hospital, most patients felt rushed and information was not explained in a way that made sense to them. "There is a need in hospitals that pharmacists could fill by taking the time to explain the medications to their patients, especially those with disabilities, in a more patient-centered way," said Kramer.



Bassett, Gatland, and Awugah work onsite at the Hospital for Special Care's fully equipped pharmacy to meet the unique needs of patients with extremely complex and often multisystemic medical challenges.

One of the most important things pharmacists can do is learn about potential communication barriers with Deaf or hard of hearing patients and the most effective techniques to overcome them.

"The biggest issue I hear from Deaf patients about community pharmacists is that they did not look at them," said Kramer. "Many Deaf patients need to see your lips to understand what you are saying. If you look away while speaking or talk to them with the computer blocking your mouth, they may have difficulty understanding."

In these cases, pharmacists should face the patient, talk normally, and be prepared to repeat what they said. They also should not assume that the patient understood the information if they nod. "There is the 'Deaf nod' in the Deaf community," said Kramer. "This just means 'oh yeah' or 'go on,' not necessarily 'I understand 100% how to take this medication.' " If the patient has an interpreter present, do not ask the interpreter to tell the patient something, but rather, talk directly to the patient, he continued.

"Write things down, too," Kramer said, or type them on your phone. While many Deaf individuals are able to lip-read, it is very difficult to do. It is important to keep in mind that many Deaf patients grow up with ASL as their first language and English their second. For these patients, writing things down may not be enough. "Pictures are a great way to explain things," he said.

A number of resources and technology exists to better assist patients who are deaf, hard of hearing, or deafblind. For instance, AdhereTech's Smart Pill Bottle sends notifications to patients via text or call when they miss a dose, and the app Otter.ai transcribes speech to text. Surgical masks with a clear section over the mouth to allow for lip-reading is another simple way to make hospitals more accessible.

"Deaf patients may even request pharmacists to talk to them at home, where they can have access to a video remote interpreter (VRI)," said Kramer. Many hospitals already have VRI in place, he said. In these cases, it's important to verify that the interpreter has medical interpreting experience.

Patients who are blind or have low vision have a different set of needs about which pharmacists need to be aware. According to the U.S. Access Board Working Group, people who are blind or have visual impairments and cannot read print prescription labels are at risk of taking "the wrong medication, the wrong amount, at the wrong time, and under the wrong instructions."

Accessible prescription labels, such as those printed in braille or large print, can help lower these risks for patients. "ScripTalk and other verbal speaking prescription labels are helpful," said Kramer, especially because they are more accessible for caregivers who may not know braille.

And while every pharmacy may not have a braille printer or is able to utilize audible labels, pharmacists should know what resources are available—especially if they have a regular patient who is blind or has low vision. That way, they can make arrangements that would best serve the patient's needs.

As far as leading blind patients within the pharmacy, don't grab their hand and pull them, said Kramer. Rather, let them take your shoulder. "This naturally puts them a step behind you, allowing them to feel you moving up or down on the terrain," he said.

It's also imperative that pharmacists address the patient's actual concerns and reason for the visit. Patients often report that providers "spent more time going over [their] disability and the events leading to it, rather than the appointment's actual goals," said Kramer.

Above all else, don't assume. Pharmacists should ask patients with disabilities how they can best assist them and leave a note for the next provider. "No one knows their disability better than the patient," said Kramer.

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