HCQU CARES

NURSING EDITION

MANAGING AND ENABLING NURSING WORK FOR QUALITY HEALTHCARE OUTCOMES:

Education of Caregivers is Essential

Caregiving is all around us. In the words of former First Lady Rosalyn Carter, “There are only four kinds of people in the world — those that have been caregivers, those that are caregivers, those who will be caregivers, and those who will need caregivers.”

According to the American Nurses Association, two of the roles of a nurse are to “provide health promotion, counseling, and education and to coordinate care” (American Nurses Association, n.d.). For nurses working with people who have intellectual disability/autism (ID/A) and may be dependent on others to facilitate their care, the need for coordination of information and education with direct caregivers is of paramount importance. Caregivers play an essential role in the daily lives of people with ID/A, quite often serving as a primary advocate and support system for them. Educating a caregiver about understanding specific needs, recognizing potential health issues, and responding appropriately can promote better health outcomes, improve safety, and increase overall well-being for individuals in their care.

In 2018, a research study was conducted in the United Kingdom to understand the role of nurses and how the nursing profession has been traditionally defined. The study found that rather than associating their work with tasks to complete, nurses felt their work encompassed three areas: clinical work, managing work, and enabling work. Nurses who work with people who have ID/A and their caregivers perform in all 3 categories, but their prime responsibilities tend to be in the categories of managing work, where care environments are sustained and others are enabled to provide the care, and enabling work, where education is provided to others to improve quality in nursing and healthcare outcomes (Jackson et al, 2022). In the article discussing this study, a nurse who worked in disabilities nursing stated, “I see my role as supporting people with learning disabilities to understand and manage their health needs and supporting other services to understand and manage the health needs of people with learning disabilities” (Jackson et al, 2022).

Knowledge about various health conditions and implementation of timely and appropriate care can make the difference between quality of life and poor health outcomes for people with ID/A. Nurses working within the ID/A service system have a responsibility to educate caregivers to increase their capacity to provide quality healthcare.

This issue of *HCQU Cares: Nursing Edition* focuses on educating caregivers to recognize and appropriately respond to emergency situations.

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EDUCATING CAREGIVERS

Teach: Look for the reason for behavior

Teach: Always rule out medical causes first when thinking about behavior

The misconception that a person's behavior is an intentional attempt to manipulate the environment and/or control the situation can prevent a caregiver from seeking emergency services when they are needed. The agency nurse is responsible for teaching caregivers that people with ID/A often communicate physical symptoms through behaviors that others find challenging. For example, a person with a toothache might repeatedly slap the side of their face or bang their head. A cavity left untreated could lead to sepsis and other medical conditions, especially cardiac conditions. Likewise, a person who is constipated might hit their abdomen or stop eating. The lack of bowel movement will eventually cause a bowel obstruction.

When a person presents a behavior that challenges, it is best practice to consider possible physical/medical reasons first; 75% of the time, the behavior is related to the person's physical health (Kripke, 2016). A caregiver taught to perceive behavior as communicating a physical symptom might identify an untreated or undiagnosed health condition that is causing discomfort and perhaps prevent a medical emergency.

Educate caregivers on differentiating between a person's typical behavioral responses, known as the person's baseline, and genuine signs of distress or medical emergencies. The ability to identify a medical emergency based on non-baseline behavior enables caregivers to activate emergency services more quickly to prevent permanent tissue damage and potential loss of life. Tips for educating caregivers to correctly identify and respond to medical emergencies include:

- Establish clear protocols and guidelines to be followed when an emergency is suspected; emphasize the importance of erring on the side of caution and activating emergency services immediately, before notifying agency personnel.
- Educate on symptoms that warrant immediate action, such as sudden changes in behavior, significant alterations in vital signs, and unusual physical symptoms.
- Discuss disease progression and encourage seeking medical attention at the first sign of a problem, before it becomes an emergency.
- Present common interpretations of various behaviors (if not person's baseline behavior):
    - Head banging or slapping: ear infection, headache, dental concern, sinus infection
    - Intense rocking: headache, chest pain, abdominal pain, urinary tract infection
    - Scratching: gastritis, ulcer, pancreatitis, gallbladder disorder
    - Self-restraint: seizures, movement disorder, PTSD, abdominal pain
    - Smearing feces: rectal/anal/vaginal injury, infection, or irritation; hemorrhoids; parasites
    - Teeth grinding: Sinus pain or pressure

The interpretations listed above are based on the observations of Dr. Ruth Ryan, a subject matter expert in the field of intellectual disabilities who has devoted her practice to working with people with developmental disabilities (Ryan, 2013). Encouraging caregivers to seek medical attention upon observing any of the behaviors listed can result in a person getting the appropriate treatment in time to avoid a medical emergency in the future.

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TEACH: RECOGNIZE EMERGENCIES AND CALL 911 IMMEDIATELY

The HCQU's *Emergency Care: When to Seek* training describes many situations requiring emergency intervention. It is a good resource for caregivers to enhance their knowledge on this topic.

The Office of Developmental Programs distributed a health alert titled, "Call 911 in a Medical Emergency", to explain the importance of calling immediately when emergency assistance is needed. It states, "There are two key issues in reducing this risk for delay (in calling 911): Recognizing a medical emergency and seeking immediate attention for the emergency." The alert is available at: https://os.provideralliance.org/wp-content/uploads/2023/04/2023-ODP-Health-Alert-04-19-2023-CALL-911-IN-A-MEDICAL-EMERGENCY.pdf. Take time to review the information with caregivers.

It is the responsibility of agency nurses to teach caregivers to understand what constitutes a medical emergency and when to call 911. This requires agency nurses to:

- Prioritize education around identifying medical emergencies and instruct caregivers to call 911 without delay. Educate them about the significance of acting quickly to avoid negative outcomes for the person. You might consider creating one-page medical emergency topic sheets, educating caregivers monthly to ensure their awareness of the importance of each topic, and encouraging them to keep the information readily accessible.
- Debrief with caregivers after a medical emergency event to discuss how the event was handled, if it was handled at the right time, and if other actions might have led to better outcomes.

Embrace the roles of managing and enabling nursing work as an agency nurse by (1) teaching caregivers the knowledge they need to recognize emergencies and respond in a timely fashion to improve health outcomes and (2) assisting people with ID/A, as needed, to effectively manage their healthcare needs.

Happy Nurses Day!

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