

Spring 2020 Issue

“When you are a nurse you know that every day you will touch a life... and a life will touch yours.”



Spring 2020 Nurse's Newsletter

According to the American Nurses Association (ANA), nursing practice involves “the protection, promotion, and optimization of health and abilities, prevention of illness and injury, alleviation of suffering, and advocacy in the care of individuals, families, communities, and populations”. In its Code of Ethics, the ANA states, “the nurse promotes, advocates for, and protects the rights, health, and safety of the patient. Aspects of advocacy include nurses communicating, educating, acting as a liaison, and providing quality care to achieve healthy outcomes” (Alvernia University, 2016).

Nurses caring for people with intellectual and/or developmental disabilities (I/DD), which include autism, practice advocacy daily – coordinating medical appointments with providers who are experienced in caring for this population, providing patient-centered information to healthcare professionals to enhance care, and educating direct support professionals, for example. Nurses working in the I/DD field understand that people want a voice in their healthcare and deserve to be treated with compassion, dignity, and respect.

Last year, the ANA issued a position statement on the care of people with disabilities in a publication titled, Nurse's Role in Providing Ethically and Developmentally Appropriate Care to People with Intellectual and Developmental Disabilities. Principles from that document related to advocacy are explored in this issue of HCQU Cares: Nursing Edition.

A Voice to Lead - The Nurse as an Advocate

NURSING ADVOCACY STORY: MY SMILING HEART

Jake was a 67-year-old man with mild intellectual disability (I/DD) who worked at the local grocery store in my community. I talked with Jake on several occasions as I was out grocery shopping. Jake always told me how much he enjoyed working at the local grocery store and about his sister, who helped him his whole life. I admired Jake's zest for life, his work ethic, and his close relationship with his sister. For 4 years, I had been working for a local group home that supported people with I/DD. One day I received a phone call from the administrator to alert me about a patient with a poor prognosis being admitted to our facility from the hospital. My heart felt saddened to learn that the patient was Jake. I contacted the hospital for more information and requested to speak with the social worker. The social worker stated that Jake had suffered a severe stroke. He had pinpoint pupils, and he could not talk, walk, or eat. During his hospitalization, a feeding tube was inserted, due to the risk for aspiration.

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Jake did not look well upon arrival at our facility. I was surprised to see his discharge instructions contained no orders for treatment or comfort care; the only order was to follow-up with his doctor in a week to discuss hospice services. I kept remembering the man Jake was when I saw him in the grocery store and knew I had to advocate for him. First, I contacted the social worker, who replied that any concerns could be addressed at the one week follow-up appointment with the current primary care physician. Next, I contacted Jake's physician to schedule a more rapid follow-up. At the appointment two days later, all concerns were presented and discussed. The physician ordered speech therapy, occupational therapy, and physical therapy but wanted to monitor Jake's progress monthly for the next 6 months before deciding about hospice services. Someone from the home health agency arrived the very next day to begin their assessment and treatment plans.

Over the next 6 months, Jake responded beautifully to the care of the entire multidisciplinary team; he began walking, talking, eating and gaining weight. I couldn't believe it, and neither could the doctor. At the next appointment, she said she was very impressed with Jake's progress. Jake smiled and said, "My friends at home help me all the time!" This statement made my heart smile. It was in that moment that I knew the reason I became a nurse. My heart continues to smile every time I think about Jake!

A VOICE FOR THE VULNERABLE

Nurses have a unique position on the frontline of healthcare to advocate for all patients, including individuals with I/DD. This edition of KEPRO's HCQU CARES: Nursing Edition newsletter examines the nurse's role as patient advocate. Advocacy consists of many actions – representing the patient, defending the patient's rights, contributing to and supporting a patient's decisions, and being a voice for the vulnerable (Davoodvand, et al., 2016). Other ways a nurse can advocate dynamically include ensuring patient safety, educating patients, and connecting patients to valuable resources (Nitzky, 2018).

The American Nurses Association (ANA) states that "nurses provide essential services, are knowledgeable

about client needs, and interact closely with health care consumers across a variety of care settings and social groups” (ANA, n.d.). Such interaction provides nurses with a comprehensive understanding of the health needs of various populations and positions them to help people navigate the complex health care delivery system. “Nurses can enhance the quality of life for people with IDD through advocacy efforts to break down traditional barriers, bias, stigmas, and stereotypes” (ANA, 2019). According to the Position Summary of The Arc, “Advocacy is essential for promoting and protecting civil and human rights of people with IDD and for establishing, maintaining or improving their quality of life.” Without advocacy at all levels, people with I/DD might not have knowledge of or access to necessary supports, or the ability to exercise basic human rights (The Arc, 2020).

ADVOCACY SPOTLIGHT: SEXUAL ABUSE OF MEN & WOMEN WITH I/DD

People with I/DD are 2.5 to 10 times more likely to experience abuse during their lives and are more likely to experience recurring abuse. Most incidences of abuse are not reported, and when reported, most cases do not lead to a conviction. In many instances, the abuse is perpetrated by someone the person with a disability knows (National Association of Councils on Developmental Disabilities, 2017).

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Individuals with I/DD are 7 times more likely to be sexually assaulted than people without disabilities. This includes both men and women. Some may be surprised to learn that 32% of men with I/DD will be sexually victimized during their lifetimes; that number is 83% for women with I/DD (WEAVE of Kent County, 2018). There are several factors that increase the risk for sexual abuse in people with I/DD, including the lack of adequate and medically appropriate information regarding sexuality education, social norms, abuse awareness, and healthy relationships. People with I/DD may also lack peer relationships, which can negatively impact self-worth, interpersonal functioning, and may lead to having unhealthy relationships, that may increase the person’s risk for abuse. Several factors increase the risk for people with I/DD to experience sexual abuse, including the

lack of information about anatomy and sexual development, lack of educational resources about abuse awareness they can comprehend, education about healthy relationships and social norms, and age-appropriate friends (National Association of Councils on Developmental Disabilities, 2017). Some people with I/DD might not know how to recognize when they are victims of sexual assault, how to talk about it, or how to report it.

Healthcare professionals are in a strategic position to educate patients with disabilities about sexual violence, abuse and neglect, and how to report it. The ANA called nurses to action in its Position Statement, Nurse’s Role in Providing Ethically & Developmentally Appropriate Care to People with IDD published late last year. “Nurses are well positioned to advocate for the rights of people with IDD, as well as protect them from potentially harmful factors, such as victimization, abuse, neglect, and discrimination” (American Nurses Association, 2019). The ANA states that nurses should increase their knowledge about methods to assess and screen for abuse in people with I/DD and “become familiar with the four R’s: realize an increased risk of abuse, routine screening, recognize signs of abuse and report it (American Nurses Association, 2019).”

Statistics on abuse of people with I/DD help inform nurses about this significant problem, allowing them to make routine screening for abuse part of each clinical interaction with the person who has I/DD. Routine screening for sexual abuse involves examining all anatomical structures during physical assessment and observing for physical signs and symptoms of sexual abuse, such as physical trauma to the genital area, and/or indication of pain in areas of the body that may be associated with sexual assault, such as the genitals, breasts, anal area, and throat.

The 4 R's:

1. Recognize an increased risk of abuse
2. Routine screening
3. Recognize signs of abuse
4. Report abuse

Nurses must be able to recognize behavioral changes that may be associated with sexual abuse, which is the third R, as adults with I/DD may not present with physical symptoms. To identify worrisome behavioral symptoms that might be indicative of sexual abuse, it is necessary to learn the individual's baseline behavior (Koetting, et. al., 2012). Behavioral symptoms of sexual abuse may include difficulty walking and/or sitting, torn, stained bloody clothing, genital pain or itching, external genitalia bruising/bleeding, dramatic changes in behavior, sexually transmitted infections, pregnancy, inappropriate sexual knowledge, nightmares, and bedwetting

(HCQU training on Abuse: Recognizing and Reporting). Other signs may include resisting touch or a change in comfort with touch, noticeable increase in self-soothing behaviors, unexpected gifts, money or other items, and new behavior showing avoidance of certain people, places or activities (WEAVE of Kent County, 2018).

The 4th R is reporting. For those who are unable to self-report the nurse has a responsibility to make the report. The ANA calls for nurses to “encourage and support people with I/DD in self-advocacy and autonomy to speak for themselves when possible” (American Nurses Association, 2019). For those who can self-report the response of the nurse at the time of the report is crucial for the healing process. It is important that the individual does not feel abandoned once he or she reports abuse (Weave of Kent County, 2018). Nurses should be supportive throughout the process of reporting abuse and neglect, during the investigation, and when referring for after care. Helpful strategies include taking the time to listen, be kind, and be there for the person. Trusting and supportive relationships cause the person to feel safe, which is required for recovery from the abuse. Let's take a look at one man's story before further discussion of the 4th R.

A STORY ABOUT SEXUAL VIOLENCE: JAMES' STORY (from the Arc)

I never thought lightning could strike twice in the same place, but in my life it happened. I was sexually assaulted four times during my life and this is not uncommon for men or women with disabilities. I want to share the last time it happened to me. I was looking for a Church that welcomed people including those with disabilities. A friend encouraged me to join him for a Church service and when I was there I met a member who was deaf and wanted to teach me sign language. I thought we were becoming friends. One time we spoke on the phone and he asked if I was gay, I told him I was not. We got together the day before Church at my home and he began to be sexual with me. Even knowing I was not gay, he still approached me. Again, I told him I was not interested and let him know by shaking my head “NO” and backed away. I used sign language to say NO but he signed YES. The next day when I went to Church I didn't tell anyone.

I felt ashamed and afraid if I told anyone I could be hurt. I reached out to the pastor and nothing was done and out of frustration I told my friend and he called 211 to make a report on my behalf with my permission. I went to the hospital to make sure I was OK. People listened and took the time to help me. The SANE Nurse (Sexual Assault Nurse Examiner) was gentle and understanding. I wanted to make a formal report to law enforcement and hoped the officer would be kind and help me feel at ease. Later in the week an officer made a home visit and gathered evidence. The kindness the officer showed me is not typical. I pressed charges and went to court. He went to jail. My friends believed me and were helpful at different stages, but when I approached the local rape crisis center two weeks later they didn't know how to provide support since they do not usually help many men, especially men with disabilities. It was a new experience for them, but despite them not having training, they tried to be helpful. No one taught me the steps to recovery. I did remember what the SANE nurse told me – she looked me in the eye and said I needed to take care of myself before helping others who have suffered. After two years of recovery work, I realized when I was at a meeting to discuss sexual assault that I wanted to tell my story. This was the beginning of my journey to become an advocate to support others with disabilities who have suffered with sexual assault. I am now a national advocate and speaker at many conferences sharing my story and recommending changes so others can find healing and if they want they can become part of the MeToo movement.

Reference

The Arc. (2019, April 19). *Talk About Sexual Violence: James' Story*. Retrieved from: <https://thearc.org/talk-about-sexual-violence-james-story/>

PENNSYLVANIA REPORTING ABUSE & NEGLECT REQUIREMENTS FOR NURSES

In the above story, the actions of James, his friend, a nurse, and a police officer made a difference in James' journey to recovery from sexual violence. The Adult Protective Services Act of 2010 was enacted to provide protective services to adults age 18 to 59 who have a physical or mental impairment that substantially limits one or more major life activities. It is important to report suspected or actual cases of abuse of all types, including sexual abuse. In fact, nurses and any person or agency working with people who have I/DD who are paid by public funds are mandated reporters. Report abuse to the Protective Services Hotline at 1-800-490-8505. These calls are answered by the Area Agency on Aging, who will handle the report if the person is age 60 or greater, or contact Liberty Healthcare for people age 18-59.

People with I/DD are a vulnerable population who have experienced more abuse than the general population. The rate of sexual abuse for both men and women is extremely high. Nurses can positively impact this situation by following the 4 Rs—realizing an increased risk of abuse for this population, routinely screening for abuse, recognizing signs of abuse, and reporting actual or suspected cases of abuse. Patient, understanding, and compassionate interactions with people who have reported abuse are essential to help the person heal.

Report abuse to the Protective Services Hotline at 1-800-490-8505

NEW MEDICATION FOR SEIZURES - EPIDIOLEX

The U.S. Food and Drug Administration approved EPIDIOLEX (cannabidiol or CBD) oral solution for the treatment of seizures associated with Lennox-Gastaut and Dravet syndromes in patients ages 2 years and older (FDA, 2018). These diagnoses are rare, more severe forms of epilepsy that are often unresponsive to anticonvulsant drugs. EPIDIOLEX was approved following phase-3 clinical trials that evaluated its safety and efficacy in treatment of epilepsy. According to the prescribing information for this drug, “the precise mechanisms by which EPIDIOLOEX exerts its anticonvulsant effect in humans is unknown. Cannabidiol does not appear to exert its anticonvulsant effects through interaction with cannabinoid receptors” (EPIDIOLEX.com full prescribing information, 2020).

EPIDIOLEX is administered orally twice daily, starting with a dose of 2.5mg/kg twice daily, and can be titrated up to the recommended maintenance dose of 10mg/kg/day. Maximum dosage recommendations are 20mg/kg/day, however increased adverse effects were noted at this dose. The most common adverse effects were sleepiness, decreased appetite, diarrhea, elevated liver enzymes, fatigue, rash, sleep disturbances, and infections. Elevated liver levels were more prevalent with concurrent use of valproate and/or clobazam. Prior to starting EPIDIOLEX treatment, serum transaminases and total bilirubin levels need to be assessed. One patient during clinical trials experienced pruritus, erythema, and angioedema requiring antihistamine treatment.

Additional information:

- Food may affect EPIDIOLEX levels.
- When administering EPIDIOLEX, use a calibrated measuring device, such as a syringe.
- Inform caregivers that a household measuring teaspoon is not an adequate measuring device.
- Abrupt discontinuation of EPIDIOLEX should be avoided to minimize an increase in seizure frequency.
- Discard any unused portion 12 weeks after opening (Huizenga, 2018).
- Under the Controlled Substance Act, CBD is currently a schedule I substance, because it contains a chemical component of the cannabis plant (FDA, 2018).

More information about EPIDIOLEX can be found at this website: <https://www.epidiolex.com/>

References

- American Nurses Association. (n.d.) Advocacy. Retrieved from <https://www.nursingworld.org/practice-policy/advocacy/American Nurses Association>
- Davoodvand, S., Abbaszadeh, A., Ahmadi, F. (2016, June 11). Patient advocacy from the clinical nurses' viewpoint: a qualitative study. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4958925/>
- Disability Justice (2020). Sexual Abuse. <https://disabilityjustice.org/sexual-abuse/>
- EPIDIOLEX. (2020). Prescribing Information. Retrieved from https://www.EPIDIOLEX.com/sites/default/files/pdfs/EPIDIOLEX_Full_Prescribing_Information_04_2020.pdf#page=23
- Huizenga, Megan. (2018). Cannabinoid Science and EPIDIOLEX (cannabidiol) PowerPoint. PADDNN Conference December 2019.
- Koetting, C., Fitzpatrick, J., Lewin, L., & Kilanowski, J. (2012). Nurse practitioner knowledge of child sexual abuse in children with cognitive disabilities. *Journal of Forensic Nursing*, 8 (2), 72-80. Retrieved from <https://journals.lww.com/forensicnursing/Pages/articleviewer.aspx?year=2012&issue=06000&article=00004&type=Fulltext>
- National Association of Councils on Developmental Disabilities. (2017, November 28). Special Publication: Councils on Developmental Disabilities Addressing Sexual Violence and Neglect. Retrieved from <https://nacdd.org/wp-content/uploads/2017/11/DD-Councils-Special-Publication.pdf>
- Nursing World. (2020) American Nurses Position Statement on the Nurse's Role in Providing Ethically & Developmentally Appropriate Care to People with IDD. Retrieved from <https://www.nursingworld.org/~4ab16d/globalassets/practiceandpolicy/nursing-excellence/ana-position-statements/social-causes-and-health-care/nurses-role-in-providing-ethically-and-developmentally-appropriate-care-to-people-with-intellectual-and-developmental-disabilities.pdf>
- Nitzky, A. (2018, August 30). Six Ways Nurses Can Advocate for Patients. Retrieved from <https://www.oncnursingnews.com/contributor/alene-nitzky/2018/08/six-ways-nurses-can-advocate-for-patients>
- PA Department of Human Services. (2020) Adult Protective Services Frequently Asked Questions. Retrieved from <https://www.dhs.pa.gov/about/Fraud-And-Abuse/Documents/MR%20FAQ.pdf>
- The Arc (2019, November 19). Let's Talk About Sexual Violence Against Men With Disabilities. Retrieved from <https://thearc.org/lets-talk-about-sexual-violence-against-men-with-disabilities/>
- The Arc (2020). Position Statement: Rights Summary. Retrieved from <https://thearc.org/position-statements/rights-summary/>
- The Arc (2019, April 19). Talk About Sexual Violence: James' Story. Retrieved from: <https://thearc.org/talk-about-sexual-violence-james-story/>
- Vanover, Jason. (2016, June 29). How to Recognize the Signs of Sexual Abuse Among People with Disabilities. Retrieved from <https://www.relias.com/blog/how-to-recognize-the-signs-of-sexual-abuse-among-people-with-disabilities>
- Weave of Kent County. (2018, August 15). Working to End Assault & Violence for Everyone. Retrieved from <https://www.endabusepwd.org/wp-content/uploads/2015/01/Guardian-Toolkit-Supporting-Survivors-of-Sexual-Assault.pdf>



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