

Nursing Care for People with Developmental Disabilities

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Introduction

Persons with developmental disabilities (DDs) have complex health promotion and health care needs. Developmental disabilities may include behavioural (attention deficit hyperactivity disorder, emotional), communication (autism, social communication disorder, learning disability), intellectual (Trisomy 21, fetal alcohol syndrome, fragile X), and other disabilities that affect development and optimal functioning (physical, visual) (APA, 2013). DDs may be present at birth or develop before 18 years of age (DSO, 2016). People with DDs are twice as likely to be diagnosed with a psychiatric disorder or have poor mental health status, live in poverty, and have little access to health promotion strategies or community nursing health supports (Hatton et al., 2015). Despite their needs, people with DDs face disparities in access to health promotion, prevention, and treatment programs and services.

Nurses have the potential to significantly contribute to the health of individuals with developmental disabilities within healthcare settings and in the community. This raises the question whether nurses are well-equipped to respond to the needs of people with DDs. Nurses in health care settings report difficulties in caring for patients with DDs due to the associated communication, social, cognitive, behavioural and physical challenges. Given the increasing numbers of individuals in acute care, primary care and long-term care as well as in community health settings, some of who have DDs, nurses will be increasingly needed and challenged to integrate effective strategies into their practice.



Our Study

This Information Sheet presents select findings from our study titled “Nursing care for persons with developmental disabilities”. The overall goal of this project was to determine the state of knowledge in nursing practice in the DDs field.

We report preliminary findings on our review of the literature that looked at recommended nursing strategies as well as the challenges nurses face in providing care for persons with DDs.

Did you know?

The Canadian Survey on Disability 2017 reported that 6.2 million (22%) Canadians aged 15 years and older had at least one type of disability. Among youth, mental health-related (8%) and learning (6%) disability were identified as the most common (Statistics Canada, 2018).

The challenges in provision of nursing care for people with DDs

Lack of education and training

An important issue highlighted in the literature is the lack of education provided in nursing schools, as well as in nurses' professional career, in regards to disability studies. In a study, nursing participants felt that they had not received any orientation or education about caring for people with DDs, or in work settings (Singer, 2013).

There is limited professional development programs to provide health care for persons with DDs. Lack of training for health visitors, including nurses, was highlighted by study participants who felt that even though they have a role to play in identifying children who might have Autism Spectrum Disorder, they also stated that their competence was inadequate (Halpin & Nugent, 2007). They highlighted the need for nurses to have autism training.

The nurse–patient ratio

According to the literature, insufficient staff also impacts and magnifies problems for providing care for people with DDs. For example, the nurse–patient ratio impedes nurses to allocate more time to their patients with DDs or accommodate their needs (Ndengeyingoma, & Ruel, 2016).

Time

In hospital settings, limited time to communicate constitutes a barrier to building effective relationships between nurses and their patients with DDs with complex communication needs. Nurses fear that communication will take too long and they may avoid direct communication with the patient and depend more upon family caregivers for communication (Hemsley et al, 2012).

Time (continued)

Ndengeyingoma and Ruel (2016) raise concerns identified by nurses, specifically insufficient time to intervene adequately to emergent situations, and lack of communication regarding specific needs of person's with Intellectual Disabilities. Patients with Intellectual Disabilities need more time, more audio and visual support. Furthermore, communication between shift nurses is typically not sufficient to convey all information about the patient's medical condition, or about people with Intellectual Disabilities' behaviours, routines and their functional abilities in activities of daily living, such as eating.

Furthermore, studies point out that the lack of time to communicate with patients with DDs may be perceived by patients as a reflection of nurses' "negative or discriminatory attitudes towards them" (Hemsley et al., 2012, p. 122). This may further reinforce the cycle of social isolation and lack of participation that people with DDs experience in their everyday lives.

Communication

Enhancing communication is important for people with DDs. In the school setting for example, a study found that communication difficulties were a major challenge for the nurses (Singer, 2013). Participants highlighted difficulties in making accurate assessment, explaining procedures and interventions, not knowing if students had understood the instructions and students not being able to articulate their needs (Singer, 2013).

In other settings, studies found that nurses felt that their clinical evaluations of patients with DDs was incomplete. They felt uncertain when they completed patient's health checkup assessments or when they explained the interventions. Furthermore, they felt that they could not appropriately respond to the patient's needs (Ndengeyingoma, & Ruel, 2016).

Recommended Strategies

Empirical and applied knowledge pertaining to provision of care to those with DDs need to be available. This information will assist in developing tools, frameworks and care plans by academic scholars, policymakers and nursing educators which can be utilized by nurses and nursing students working on the frontline with the patients.

Training and education also play a crucial role in improving care, this is because nurses working within DDs require specialized education and training programs. Currently, models of health care transition programs for adolescents with DDs are in their early stages of development (Betz, 2007). These models will serve as an asset for nurses and help the target population to transition to their next life stage with decreased limitations.

To improve quality of care we need to involve multidisciplinary team members to reinforce the continuity of care (Balakas, Gallaher & Tilley, 2015). We also must include the perspectives of persons with DDs and their family caregivers. We should integrate care work with families of those with DDs. Therefore, training is needed for caregivers as is providing them with education and resources. Having multiple parties involved in provision of care allows the patient with DDs to have more support networks and these include the members of the multidisciplinary team and family members.

In order to facilitate seamless transitions within healthcare settings and the community, Raemy & Paignon(2019) suggest it may be beneficial for family members to have a comprehensive document that has pertinent information regarding the patient with DDs. This document would contain specific care preferences, communication skills, specific health history, and any other detail that is critical for their health and well-being.

Nurses will require focused resources and supports that will allow consistent care that helps ensure a safe environment for both patients and nurses. These resources include specialized tools that help working with patient's with DDs. Balakas, Gallaher, & Tilley (2015) promote an Adaptive Care Screening Tool in which various and specific interventions were adjusted and utilized to better the quality of care for those with DDs. These interventions can be adjusting the room design, playing music, tactile objects, having a consistent nurse, and promoting parent's involvement.



Through our literature review we found nurses experienced several challenges when providing care to persons with DDs including:

- Lack of orientation and adequate education on personalized care of persons with DDs, in regards to providing support, communicating in relation to their needs, and preparing patients with disabilities for procedures.
- Lack of time to undertake educational modules on care of persons with DDs.
- Providing nurses specific and focused resources, enhances consistent care and also ensures a safe environment for both nurses and their patients.

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ABOUT THE INFORMATION SHEET

This information sheet is in a series of knowledge transfer outcomes produced at our Office as part of the *Intersectional Approach to Immigration Status, Gender and Disability Research Program*. It provides preliminary findings of our ongoing study titled *Nursing care for persons with developmental disabilities*.

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