Guest Editorial

Victoria Has a Developmental Disability

Victoria Maple (pseudonym), age 68, has a primary diagnosis of a developmental disability due to Down syndrome. Until 5 weeks ago, she lived with her mother and father. Upon the death of her mother, her father, Daniel, 91 years old and in declining health, moved Victoria into a nursing home. Staff have noted that Victoria is moderately overweight, has mild hearing loss, and demonstrates signs of early-stage dementia.

Developmental disability (DD) describes a population of individuals with significant limitations in intellectual functioning and adaptive conceptual, social, and practical behavior skills that start before age 18. It is a term that is now used instead of the phrase “mental retardation” (Schalock et al., 2007). Generally, individuals with DD experience the same physical process of aging as individuals without life-long disabilities, with the exception of those individuals who have Down syndrome. These individuals may show physical signs of aging as much as 20 years earlier than seen in the general population (Strax, Luciano, Dunn, & Quevedo, 2010).

Individuals with moderate or severe DD are now routinely living into their late 50s and 60s. For example, in a sample of 29,290 individuals with DDs living in residential facilities in the Netherlands, researchers determined that those who were 20 years old had a life expectancy of 44 more years; thus, these individuals are expected to live into their early 60s (Maaskant, Gevers, & Wierda, 2002). As these individuals age, their health and functional abilities decline, and their nursing care and health service requirements change. Increasingly, some of these individuals will be entering long-term care facilities. However, the current geriatric care system has little or no experience caring for clients aging with DD.

The nursing and health care needs of individuals with DD are often complex, and the needs become more challenging as these individuals age. The question must be asked: Are gerontological nurses prepared to effectively meet the needs of this unique group of aging individuals? Contributing to the complexity, many individuals with DD cannot verbally communicate about their symptoms. Some symptoms may appear as behavioral challenges rather than health problems.

We can be guided in our work with this unique group of individuals by gerontological nursing care principles, beginning with the assessment of their functional status to determine appropriate interventions for developmental aging, health challenges, and health promotion needs. Our nursing interventions must be personalized according to the individual’s preferences and health status. Key goals will include: preventing...
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promoting optimum physical, mental, and social functioning. Attention to communication strategies and simple adaptations to the environment can optimize their ability to engage in daily activities.

Individuals who are aging with DD often need to be educated about aging changes, as they tend to lack knowledge of the age-related issues they face. Providing them with accessible information at a level they can understand will enhance their ability to communicate with us and other health care professionals. We can also provide this client group and their families with anticipatory guidance about life transitions during the aging years including end-of-life care. Resources for special needs planning should be provided to families of individuals with DD, including how to set up a will and trust to preserve eligibility for benefits such as Medicaid, as well as planning for the death of the parent/caregiver.

Dialogue with adults who are aging with DD should include how to best empower them to participate in their own health care. Such action is consistent with the basic principles of normalization and rights recognition.

As gerontological nurses, we have some challenges ahead of us to ensure that adults aging with DD receive appropriate and effective nursing care. However, as George Patton once said, “Accept the challenges so that you can feel the exhilaration of victory” (BrainyQuote®, n.d.).

REFERENCES


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