COURSE #36644 — 5 CONTACT HOURS Release Date: 07/01/22 Expiration Date: 06/30/25

Caring for the Adult with Developmental Disability

HOW TO RECEIVE CREDIT

- Read the enclosed course.
- Complete the questions at the end of the course.
- Return your completed Evaluation to NetCE by mail or fax, or complete online at www.NetCE.com. (If you are a Florida nurse, please return the included Answer Sheet/Evaluation.) Your postmark or facsimile date will be used as your completion date.
- Receive your Certificate(s) of Completion by mail, fax, or email.

Faculty

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Faculty Disclosure

Contributing faculty, Connie Vogel, PhD, ANP, has disclosed no relevant financial relationship with any product manufacturer or service provider mentioned.

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Division Planner/Director Disclosure

The division planner and director have disclosed no relevant financial relationship with any product manufacturer or service provider mentioned.

Audience

This course is designed for all nurses, especially those who are or may be caring for adults with developmental disabilities.

Accreditations & Approvals

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A complete Works Cited list begins on page 25.

About the Sponsor

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Disclosure Statement

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Course Objective

The purpose of this course is to provide specific information about some of the unique physical and mental health problems that may occur in adults with developmental disabilities and to suggest approaches to care that will best ensure compliance and cooperation.

Learning Objectives

Upon completion of this course, you should be able to:

1. Define intellectual disability, mental retardation, and developmental disability.
2. Cite specific barriers in providing optimal health care to patients with developmental disabilities.
3. Discuss health conditions that commonly occur with specific types of developmental disabilities.
4. Explain mental health problems that may occur with intellectual disability.
5. Identify pharmacologic and nonpharmacologic approaches to treating mental health issues in those with developmental disabilities.
6. Discuss approaches to providing quality care to adults with developmental disabilities, including techniques for working with families and caregivers.

EVIDENCE-BASED
PRACTICE
RECOMMENDATION

Sections marked with this symbol include evidence-based practice recommendations. The level of evidence and/or strength of recommendation, as provided by the evidence-based source, are also included so you may determine the validity or relevance of the information. These sections may be used in conjunction with the course material for better application to your daily practice.

INTRODUCTION

Individuals with developmental delays are living longer and in a variety of settings. Although some individuals may live with aging parents, many adults classified with developmental disability (DD) live in residential facilities, group homes, supervised apartments, or possibly independently with some outside supervision. They are likely to be seen in a variety of healthcare settings including emergency rooms, physicians' offices, inpatient settings, and for health maintenance care. Nursing care for individuals with DD is focused on assisting them to attain and maintain an optimal state of wellness across their natural life span. This goal may be complicated by a number of factors, including the physical and mental health conditions that often occur with developmental disabilities, lack of resources available, and in some instances, the attitudes and lack of knowledge of healthcare providers.

The purpose of this course is to provide specific information on some of the unique physical and mental health problems that are often found in individuals with DD. This course will also suggest approaches to care that will best ensure cooperation and compliance from the individual receiving care. There will be discussion of health maintenance needs, changes related to aging, and ethical issues involved in providing health care to this unique and interesting population. Although much of the research provided is focused on individuals with Down syndrome, the findings and recommendations may be applicable for patients with a variety of developmental disabilities.

DEFINITIONS AND TERMS

The terms "developmental disability" and "mental retardation" are sometimes used interchangeably. In actuality, developmental disability is a broader classification, and mental retardation is one developmental disability that has multiple causes. Developmental disability refers to a wide variety of severe chronic conditions, originating before 18 years of age, due to mental and/or physical impairments, that interfere with an individual's ability to function in daily living at an effective level [1; 2].

It is important to note that "mental retardation" and "intellectual disability" (ID) are two terms for the same condition; however, the term "intellectual disability" has gained currency as the preferred term. It is critical that both terms be precisely synonymous in definition and in all related classifications because federal and state laws contain the term "mental retardation." This term is used in law and public policy to determine eligibility for state and federal programs, including the Individuals with Disabilities Education Act (IDEA), Social Security Disability Insurance, and Medicaid Home and Community Based Waiver. The term "mental retardation" is also used for citizenship and legal status, civil and criminal justice, early care and education, training and employment, income support, health care, and housing and zoning [2].

The change in terminology from "mental retardation" to "intellectual disability" additionally reflects a revised focus [2]:

- It is less offensive to persons with disabilities.
- It is more consistent with internationally used terminology.
- It emphasizes the sense that intellectual disability is no longer considered an absolute, invariable trait of a person.

- It aligns with current professional practices that focus on providing supports tailored to individuals to enhance their functioning within particular environments.
- It opens the way to understanding and pursuing "disability identity," including such principles as self-worth, subjective well-being, pride, engagement in political action, and more.

Intellectual disability is characterized by a significantly subaverage intellectual functioning that includes an intelligence quotient (IQ) below 75 on individually administered tests, onset before 22 years of age, and concurrent deficits in adaptive functioning in several areas [2]. A person's level of intellectual disability may be defined by their IQ or by the types and amount of support they need (adaptive functioning) [1; 3]. The American Association on Intellectual and Developmental Disabilities (AAIDD) definition of intellectual disability focuses on adaptive skills and interactions between the person and his or her environment [2; 4]. While the IQ test is a major tool in measuring intellectual functioning, other tests focus on limitations in adaptive behavior, which covers three types of skills [2]:

- Conceptual skills: Language and literacy; money, time, and number concepts; and self-direction
- Social skills: Interpersonal skills, social responsibility, self-esteem, gullibility, naïveté (i.e., lack of wariness), social problem solving, and the ability to follow rules, obey laws, and avoid being victimized
- Practical skills: Activities of daily living (personal care), occupational skills, health care, travel/transportation, schedules/routines, safety, use of money, and use of the telephone

Although more encompassing and likely more useful in treatment planning for the intellectually disabled patient, a significant problem with providing a complete definition is its complexity. Consequently, the major function of the AAIDD is to publish the most advanced thinking on intellectual disability in order to help healthcare teams use the term effectively. In defining and assessing intellectual disability, the AAIDD has stressed that healthcare professionals should consider impacting factors, such as community environment that is typical of the individual's peers and culture, linguistic diversity, and cultural differences in the way people communicate, move, and behave [2]. Finally, from a practical standpoint for the healthcare provider who is not solely focused on working with a developmentally disabled population, the term may be helpful in determining what type of approach will be needed to complete a procedure or provide specific care [5].

BARRIERS TO CARE

Many complex factors lead to vulnerability in persons with intellectual disabilities, including inadequate access to essential health services and other basic services (***Table 1***) [6; 7]. A 2002 report of the U.S. Surgeon General concluded that the U.S. healthcare system failed to meet the changing needs of people with an intellectual disability and that these people often receive inferior care. The goals stated in the report are to [8; 9; 10; 102]:

- Integrate health promotion into the community environments of individuals with intellectual disabilities
- Increase knowledge and understanding of health and intellectual disability, ensuring that the knowledge is made practical and easy to use
- Improve the quality of health care for individuals with intellectual disabilities

BARRIERS TO HEALTH CARE FOR ADULTS WITH DEVELOPMENTAL DISABILITY

Domain	Effect
Mobility	Difficulty accessing health services
Sensory impairment	Reduced communication and comprehension of health processes
Behavior problems	Difficulty in examination and investigation of disease
Communication	Reduced comprehension of health processes Difficulty in presenting disease owing to reduced communicative skills Poor communication skills of health professionals
Knowledge, attitudes, and accessibility of specialist services	Poor professional knowledge Attitudinal barriers to accessing care

Source: [6; 7] *Table 1*

- Train healthcare providers in the care of individuals with intellectual disabilities
- Ensure that healthcare financing produces good health outcomes for individuals with intellectual disabilities
- Increase sources of healthcare services for the estimated 7.3 million people in the United States with intellectual disabilities

The report also noted that the treatment of individuals with an intellectual disability is seldom addressed in the training of nurses, physicians, and other healthcare providers [9; 11].

There have been indications that exposure to working with individuals with DD early in a training program will increase the likelihood that practitioners will accept this population group into their practice [9]. Hopefully, this will be motivation for additional education programs to be made available to physicians, dentists, nurses, and other healthcare providers. A majority of nurses that responded to a survey on education and training in developmental disabilities reported little or no training in this area as well as no further continuing education on the topic [13]. Integration of curriculum about the nursing care of people with DD into basic nursing education at all levels may improve the education of nurses and other healthcare providers and directly benefit the affected individuals [14].

Providing care to those with DD is difficult due to a lack of awareness of healthcare needs and required tests and procedures. In a busy healthcare system, there is often not enough time spent explaining procedures, treatments, and care to patients. Allowing the individual to become familiar with personnel and equipment that will be used in patient care may be helpful in obtaining cooperation, but it is not always done because of time constraints. Scheduling appointments at a time when a family member or advocate can accompany the individual and be there to help communicate what is expected during a procedure is beneficial but also may not occur. Unfortunately, failure to take the time to establish rapport, explain procedures, and introduce a degree of comfort and safety to the patient may result in a partially finished procedure or test and unusable results. Time spent familiarizing the individual with healthcare providers and with the equipment may result in improved care for the individual with DD and satisfaction for the healthcare provider [5; 7; 15].

Difficulties in finding, keeping, and ensuring the competence of the direct support workforce in community developmental disability services is another challenge for individuals, families, providers, and policy makers. The recruitment and retention of competent direct support staff has been widely reported as one of the most significant barriers to the sustainability, growth, and quality of community services for people with DD [11; 16].

Financial constraints are also a factor in providing quality care to individuals with DD [11]. Even routine health maintenance may cost more for these patients. For example, some individuals find it difficult to cooperate with gynecologic exams and dental care; sedation may be necessary. This process has numerous ramifications, including risk to the individual and liability of the providers. It is also significantly more expensive than if the exams and procedures were to be completed in an office without anesthesia.

Because people with DD are living longer, they are more likely to develop chronic diseases that are associated with aging. Additionally, some physical conditions are seen with increasing frequency among specific types of DD and/or ID, including seizure disorders, hypothyroidism, obesity, early onset of arthritis, and Alzheimer-type dementia [12; 17; 18]. The result is added cost to a healthcare system that is already struggling with limited financial resources [12].

A number of problems occur in financing care for those with DD. For example, Medicaid covers most individuals and, in some cases, Medicare may provide coverage. Families may also have insurance policies that provide some support, but this is less likely for adults. Because Medicaid provisions vary from state to state, there are disparities in what is covered. Dental care is one type of care that is often not included in the coverage, and the result may be a total lack of dental services for some individuals. A 2022 report from the National Council on Disability noted that 12 states do not provide basic dental benefits for those with I/DD, despite finding that those states would return $3.3 million per year, collectively, on their investment in dental care due to reduced burden of disease from conditions associated with poor oral health [102]. In addition to concerns about what Medicaid may cover, there is also difficulty finding providers who will accept Medicaid, placing another limitation on available services [11]. There are a variety of policy issues associated with Medicaid managed care, and the total effect that managed care may have on services for those with DD is not, as yet, totally understood [19]. Overall, the financial issues associated with meeting the healthcare needs of a growing DD population are significant [19; 20].

The report of the former Surgeon General included a goal to "ensure effective healthcare financing" [9]. The specifics include measures to evaluate financing packages available, create models for health maintenance that will be affordable, and use these models to "leverage" appropriate care at a reasonable price. The report also suggested increased reimbursement for healthcare providers who become skilled in providing health care to the DD population [9].

Public financial support for ID in the United States grew from $2.3 billion in 1955 to $82.6 billion in 2004, and the federal government emerged during this period as the principal provider of such support [21]. The Administration on Intellectual and Developmental Disabilities (AIDD) has established three state-based programs (i.e., the Developmental Disabilities Grant Programs) that collaborate with each other as well as with other entities in their respective states. The three state-based programs include [22]:

- State councils on developmental disabilities: Federally funded programs charged with identifying the most pressing needs of people with DD

- State protection and advocacy agencies (P&As): Provide protection for individuals with DD by empowering and advocating on an individual's behalf
- National network of University Centers for the Excellence in Developmental Disabilities Education, Research, and Service (UCEDD): Grants awarded to public service units of universities or public or not-for-profit entities associated with universities for supporting the operation and administration of such centers and for implementing core activities (i.e., interdisciplinary training, community service, research, and information dissemination)

A fourth program—Projects of National Significance (PNS)—is directed toward national concerns. PNS funds provide grants, contracts, and cooperative agreements to public and private, nonprofit institutions to create opportunities for individuals with DD.

Inequities continue to persist, however, in the distribution of financial resources and services across states, communities, families, and individual disabled consumers. Many persons with intellectual disabilities continue to live in institutions and nursing homes, and waiting lists and the number of aging caregivers are growing rapidly. Also, research and training support has declined significantly in comparison to the growing financial commitments for services and income maintenance [21].

HEALTH PROBLEMS

Individuals with DD are likely to have a variety of health problems. Some of the health problems are inherent with their disability, and treatment may start in infancy to correct or ameliorate the effects of specific disabilities and conditions. Other health problems develop with aging and lifestyle habits. Diabetes, high cholesterol, hypertension, and obesity are a few of the health problems that occur frequently in the general population but are even more likely to be present in many individuals with DD [23].

Concerns about health care for those with DD have been present for a long time. Until recently, however, there has not been a clear understanding of specific healthcare needs. The previously mentioned Surgeon General's report was largely initiated by findings from the 1995 Special Olympics, where nearly 20% of the participants with DD required immediate medical care [8].

Certain types of developmental disabilities carry with them an increased risk of specific physical health problems. The most work in this area has been done with trisomy 21, commonly known as Down syndrome. Down syndrome was first described in 1866 by a British physician who identified problems with circulation and coordination [103]. Over time, a variety of health problems have been identified as being associated with Down syndrome, which has added to the general knowledge of physical health problems and developmental disabilities. Therefore, much of the specific information regarding health concerns and care may refer to patients with Down syndrome.

CONGENITAL CONDITIONS

Heart Conditions

Congenital heart conditions occur in about 50% of infants born with Down syndrome [25; 26]. Screening by a pediatric cardiologist is essential, and surgical correction of defects is often necessary. Throughout their life span, individuals with Down syndrome should have follow-up care by a cardiologist [27]. Many individuals with Down syndrome will require subacute bacterial endocarditis prophylaxis with antibiotics prior to any invasive procedures or treatments, including routine dental care [25; 28]. The American Heart Association recommendation states that antibiotic prophylaxis is not necessary for all individuals with certain heart conditions; the change in recommendation did not specifically address patients with DD [96]. The American Heart Association recommendations indicate that individuals with previous heart surgery should continue to take antibiotics before invasive procedures.

Further medical management may include the use of medications including digoxin, ACE inhibitors, and diuretics to prevent early heart failure [106]. Mitral valve prolapse (MVP) is a common congenital occurrence, and in those with Down syndrome, there is an increase in valve-related problems as the individual enters adulthood. Echocardiograms are often indicated in adulthood to follow up on the impact of congenital heart conditions and to assess changes related to aging [17; 28]. Nurses should be alert for changes in fatigue level, shortness of breath, hypertension, or other signs of increasing cardiac difficulties.

Anatomic and Orthopedic Conditions

A number of problems may occur in individuals with DD, especially in those with Down syndrome, due to the structure of the head and neck. Ear problems often occur because of a shortened eustachian tube, resulting in serious ear infections [24; 26]. Because chronic respiratory disease is common with frequent infections, it has been suggested that individuals with Down syndrome receive pneumococcal and influenza vaccines to reduce the risk of life-threatening respiratory infections [24].

The facial structure of people with Down syndrome is characteristic and usually presents with a small mouth, high palate, and short neck. When combined with obesity, these characteristics increase the risk of obstructive airway disease and sleep apnea. Studies have suggested that nearly all persons with Down syndrome have some form of sleep-related obstruction [104]. Daytime sleepiness, irritability due to fatigue, snoring, and periods of apnea during nighttime sleep should be evaluated. Sleep apnea should be treated because it can lead to other serious long-term problems, such as pulmonary hypertension, heart failure, and even death [17; 26]. Tonsillectomy and adenoidectomy may be indicated, but often sleep apnea persists after surgical intervention [25; 104]. Other surgical interventions may be considered for persistent sleep apnea, including uvulopalatopharyngoplasty, midline posterior glossectomy, lingual tonsillectomy, genioglossus advancement, hyoid advancement, and craniofacial surgery (e.g., mandibular and midface advancements). In some individuals, positioning with pillows or raising the head of the bed may be sufficient. In others, use of a continuous positive airway pressure (CPAP) machine may be beneficial [17; 104]. Patience is required on the part of caregivers in order to help individuals learn how to use the CPAP machine. However, the improvement in rest and general feeling of well-being that comes with sleeping well may be an additional motivator. It is important to note that some patients with DD have sensory disorders or are hypersensitive to forms of touch. For these patients, use of a CPAP machine may be intolerable.

Individuals with DD who do not have sleep apnea may have other problems with sleep. For example, they often tend to have more restless sleep with intermittent myoclonic jerks, decreased oxygen saturation, and the potential for restless legs syndrome [17]. Interrupted sleep may contribute to daytime irritability and can be misinterpreted as a mood disorder. Individuals who demonstrate irritability should have their sleep pattern evaluated; behavioral assessments may also be indicated [24].

SIGNS AND SYMPTOMS OF ATLANTOAXIAL INSTABILITY IN PATIENTS WITH DOWN SYNDROME
Gait disturbances
Spasticity
Abnormal neurologic reflexes
Babinski responses
Increased deep tendon reflexes
Weakness
Clonus
Neck pain
Torticollis
Change in gait
Loss of upper or lower body strength
Change in bowel or bladder function

Source: [28] *Table 2*

Atlantoaxial and atlanto-occipital instability are conditions that occur in about 10% to 20% of individuals with Down syndrome; however, actual spinal compression is rare [24; 25; 26; 28]. Atlantoaxial instability is a term that refers to increased mobility and hyperflexibility of the cervical spine at the level of the first and second cervical vertebrae. Atlanto-occipital instability refers to a similar process in the occipital-cervical area [24]. Neurologic symptoms that may require surgical intervention can occur as a complication of this condition. Early onset of progressive arthritis of the spine is also common with aging and may manifest largely as a refusal to move [17; 25; 28]. A physical therapy evaluation may be helpful to suggest exercises that strengthen muscles and reduce trauma to the cervical spine. Cervical radiographic screening for atlantoaxial instability is no longer recommended routinely in adults, but cervical radiography in neutral, flexed, and extended positions should be considered if any of the signs or symptoms are present (***Table 2***) [28]. Pain management may become an issue as arthritis develops.

As with individuals with dementia, pain assessment can be difficult among individuals with DD [29]. Response to pain is subjective, and the same person may respond differently in different circumstances, such as when fatigued, in a strange environment, or stressed by some other occurrence. A study of nurses providing care to DD patients has indicated that moaning and crying during manipulation are the most frequent indicators of pain [30]. Facial expression, not using a specific body part, or moving in an unusual way have also been identified as indicators of pain [30]. Assessing pain and appropriately medicating are important nursing interventions in reducing overall discomfort and maintaining activity levels of DD individuals who have developed arthritis.

Subluxation of the hip and knee and various foot disorders also occur frequently in individuals with Down syndrome [17]. In addition, scoliosis commonly occurs in a variety of development disabilities, including Down syndrome, Prader-Willi syndrome, Rett syndrome, and neurofibromatosis [31; 32; 33]. Some of these conditions may be corrected surgically in childhood. In older individuals who may not have had the benefit of corrective surgical procedures, painful joints and arthritic changes are often a real problem. Efforts to utilize physical therapy interventions and appropriate pain management should be encouraged by the nursing staff [17; 30].

Sensory Conditions

Conditions resulting in hearing loss are commonplace among those with DD [7]. Unfortunately, this may lead to further communication problems, particularly if the hearing loss is profound and the individual cannot learn to sign [105]. Individuals with DD and a serious hearing loss may develop their own method of signing and expression with individuals who are familiar to them. This further illustrates the value of having a caregiver or advocate available when medical care is being provided.

Many individuals with DD, particularly those with Down syndrome, have small ear canals and examination can be difficult. For adults, use of pediatric equipment for ear exams is beneficial. Because the ear canal is small, accumulations of wax can add to hearing problems. Nurses should be aware of this and clean ears when indicated [105].

Hearing loss may result from conduction problems, sensorineural difficulties, or a combination of both [24]. Screening for hearing problems should occur periodically in childhood because some loss may not be apparent in infancy. The American Academy of Pediatrics and the Down Syndrome Medical Interest Group have recommended audiologic testing at birth and then every six months up to 3 years of age. Testing should thereafter occur annually [24]. Hearing losses that occur in adulthood may lead to behavioral changes that could be mistakenly interpreted as psychiatric problems. Hearing evaluations every three years in adulthood are appropriate.

A number of eye conditions have been associated with developmental disabilities. Estimates of the occurrence of eye conditions range from 25% in the mildly disabled to 60% in the profoundly disabled [7; 34]. Among individuals with Down syndrome, dense congenital cataracts occur at a rate of about 3% [25]. Failure to diagnose and remove cataracts will result in blindness. Accommodation problems are common, and correction with glasses may not always be completely successful [17]. Additionally, it may be difficult to get the individual to wear glasses regularly. Consequently, vision may be consistently fuzzy. There is also an increased likelihood of the development of cataracts in adulthood and at an earlier age than is seen in the general adult population [17]. Strabismus and blepharitis are also common, and blepharitis may require ongoing treatment [17; 34]. Among patients with tuberous sclerosis, retinal hamartomas or phakomas are more common [35]. Nystagmus, or involuntary eye movement, is associated with hydrocephalus, cerebral palsy, and meningitis [95].

EVIDENCE-BASED PRACTICE RECOMMENDATION

According to the College of Family Physicians of Canada, vision and hearing impairments among people with intellectual/developmental disabilities are often underdiagnosed and can result in substantial changes in behavior and in social and adaptive functioning. They recommend performing an annual office-based screening of vision and hearing or when symptoms or signs of visual or hearing problems are noticed. In addition, patients should be referred for optometry assessments to detect glaucoma and cataracts every two years after 40 years of age and for audiology assessments based on screening and for age-related hearing loss every five years after 45 years of age.

(https://www.cfp.ca/content/64/4/254. Last accessed June 10, 2022.)

Strength of Recommendation: Strong recommendation

Treatment teams should always consider the impact of hearing problems and eye conditions when planning care for individuals with DD. Regular exams will identify changes, and as a result, appropriate correction or treatment can be initiated. Behavior problems may result from sensory difficulties, and eye and ear exams should be conducted before assuming that a problem is entirely behavioral in origin. Sensory impairments may reduce the ability of the DD adult to attend medical appointments unaccompanied and may also increase their distress during consultations and physical examinations [7].

COMMON MEDICAL CONDITIONS

The cause of developmental disability in a particular individual is not always known, although research in this area is ongoing and awareness of causes and means of prevention have increased dramatically. Prenatal care, improved vaccines, and the elimination of lead paint are a few of the measures that have reduced the occurrence of developmental disabilities. In addition, the causes of physical conditions that may accompany DD are not always apparent. There are a number of physical conditions that occur in individuals with DD more often than in the general population.

Seizure Disorders

Seizures in persons with DD are likely to be severe, occur often, and be difficult to control. The prevalence of seizures increases as the degree of psychomotor retardation increases, and regularly experiencing seizures may decrease DD patients' life expectancy by up to 20 years [29]. A review of more than 2,000 deaths of individuals with DD in residential care found that 57.2% of these individuals had a seizure disorder [36]. Other studies have reported seizure disorder among individuals with DD occurring at 30 times the rate of that of the general population [37].

Assessing for seizures, administering medications appropriately, and managing the physical and psychologic aftermath of seizures are largely nursing responsibilities. Seizures may be difficult to recognize in patients with DD. In addition to generalized tonic-clonic movements, seizures may manifest as drop attacks, laughing spells, subtle tonic deviations of the eyes, or behavioral changes [38]. When one is familiar with an individual who has seizures, it is often possible to note signs that a seizure is imminent. Some individuals will have an aura or sign that they are about to have a seizure. Blurred vision, changes in light perception, or other sensory experience may cue the beginning of a seizure. If individuals can communicate this to those around them, support may be provided immediately. Even in individuals who cannot communicate clearly, it may be possible to recognize irritability or some other sign that may indicate a seizure is likely.

When individuals are experiencing a seizure, those around them should try to protect the individual from harm as much as possible, although holding them is likely to be more harmful than letting them move about. All seizures should be timed. After five minutes of continuous seizure activity, emergency services should be contacted to transport the person to an emergency department, where medication can be given to stop the seizure [38]. It is not unusual for an individual to be incontinent during a seizure, and they may need assistance after they awaken. Individuals may be confused and/or combative when the seizure is over. They should always be approached with caution. Nurses and other staff should clearly identify themselves and communicate the actions that will be undertaken. Periods of confusion can last for hours after a grand mal seizure. Often, the individual will fall into a deep sleep after the seizure is over and may awaken with no memory of it.

Management of seizures in the older adult with DD is challenging. In addition to being commonplace among individuals with DD, seizures are also often poorly controlled despite the use of multiple seizure medications in high doses. Only 40% of DD individuals with seizures remain seizure-free and controlled without toxicity [39]. Anticonvulsants or antiepileptic drugs (AEDs) are the most commonly administered medications [18; 38].

The number of AEDs available has more than doubled over the past two decades. Many of the medications have multiple side effects and drug interactions. Older patients may be more prone to side effects due to polypharmacy and changes in oral absorption and renal and hepatic metabolism. Some of the more common and important side effects of the newer AEDs include hyponatremia (with oxcarbazepine or carbamazepine), nephrolithiasis (with topiramate), aplastic anemia (with felbamate), behavioral changes (with levetiracetam or ezogabine), and vision loss (with vigabatrin) [38; 40]. All seizure medicines should be used cautiously in the anticoagulated patient, as many AEDs interact with warfarin. However, seizures should be adequately treated because of the inherent risk of brain damage and the risk of fall and hemorrhagic complications in the event of an injury [38].

In 2009, the U.S. Food and Drug Administration (FDA) issued an update following the completion of its analysis concerning the risk of suicidal behavior or ideation observed during clinical trials of various antiepileptic drugs (compared to placebo) in the treatment of epilepsy, psychiatric disorders, and other conditions. The pooled analysis of 199 clinical trials involving 11 antiepileptic drugs (i.e., carbamazepine, divalproex sodium, felbamate, gabapentin, lamotrigine, levetiracetam, oxcarbazepine, pregabalin, tiagabine, topiramate, and zonisamide) as either monotherapy or as adjuvant therapy showed that 0.43% of patients receiving an antiepileptic had suicidal behavior/ideation compared to 0.24% of patients receiving placebo. As a result of the findings, the FDA has required that the product labeling of the entire class of antiepileptics include a warning concerning the risk of suicidal behavior or ideation, and medication guides have been developed informing patients of this risk [40; 41].

Although some individuals will continue to have seizures despite being on medication, the frequency, duration, and severity of seizures may be greatly reduced. Administering the medications precisely as ordered and at the times indicated is very important. In individuals who are reluctant to take medications, all effort should be made to administer seizure medications as scheduled.

Urologic Conditions

A number of urologic conditions may be associated with intellectual disability. For example, individuals with Down syndrome are at heightened risk for several problems, including obstruction in the lower urinary tract, renal hypoplasia, and ureterovesical junction obstruction [17; 42]. Persons with Smith-Lemli-Opitz syndrome, a type of developmental disability, have been found to have upper urinary tract abnormalities at a rate of 57% and genital abnormalities at a rate of 71% [43]. Other problems that may occur in individuals with DD include renal hypoplasia, obstructive uropathy, and glomerular microcysts [44; 97]. It should also be noted that, among boys and men with Down syndrome, undescended testicles are common and the risk for testicular cancer is increased [44].

Although some urologic problems can be corrected surgically, others cannot. There is also a high likelihood of neurogenic bladders due to both poor muscle tone and, in some cases, the side effects of long-term use of medications [17]. Additionally, some individuals with DD have small bladders, which can result in poor bladder control and difficulty with continence. From a nursing standpoint, it is important to be alert for signs of urinary tract infections (UTIs). Individuals with small bladders, poor bladder tone, and possible partial obstructions in the urinary tract are at high risk for a UTI. Encouraging adequate fluid intake is a significant nursing intervention and should be a priority.

Bladder control programs are effective, and toileting on a regular schedule, usually every two hours while awake, is valuable. A 10-year follow-up study of bladder continence training in individuals with DD found that individuals involved in the study retained bladder control, and cueing as well as reminders were sufficient to help them toilet at regular intervals. The individual training programs were found to be cost effective and significantly reduced staff time [45]. The use of adult diapers may be appropriate in some cases, but this should be a decision made after discussion with the individual and his or her advocate. All intimate and personal care should be undertaken with respect for the individual's privacy and dignity [46].

Hypothyroidism

Hypothyroidism occurs frequently among adults with DD. Among individuals with Down syndrome, frequency estimates range from 13% to 50% [26]. The signs of low levels of thyroid hormone may not be obvious in those with DD. Signs include dry skin, lethargy, constipation, weight gain, and low cognitive functioning, all of which may also be signs of the disability. Most experts recommend screening with a thyroid panel every one or two years, beginning at 21 years of age [17; 25; 26].

Optimal thyroid functioning is important for cognitive functioning and normal metabolic activity. If results are abnormal, thyroid replacement therapy can be initiated. Nurses in residential and treatment facilities for adults with DD should follow up to ensure laboratory tests are being obtained. Before a diagnosis of depression or dementia is made, thyroid function should be checked [17].

OTHER CHRONIC MEDICAL CONDITIONS OF ADULTHOOD

Like the general population, individuals with DD are prone to chronic conditions that are not necessarily associated with their disability. Substantial effort has been devoted to helping adults institute lifestyle changes with diet and exercise that will help prevent chronic health problems and generally improve their quality of life. Although adults with DD have been generally excluded from these efforts, the situation has begun to improve somewhat, with efforts being made to help adults with DD improve their general health status [48; 49; 50; 51]. Because individuals with DD are living longer, they are more at risk for developing conditions associated with aging, such as diabetes and cardiovascular problems. The likelihood of these conditions occurring is increased by inactivity and obesity; therefore, developing programs that encourage physical activity and good overall health habits for patients with DD is important [49; 51; 52].

Diabetes

Type 1 diabetes has been found to be more common among individuals with DD, particularly those with Down syndrome, than among the general population [98]. Other studies have found that individuals with DD who practice dietary management and regularly exercise have no higher incidence of type 2 diabetes than the general population [52; 53]. This is a significant finding and appears to be in line with the general population's increase in diabetes along with an increase in obesity. Given that individuals with DD often tend to be shorter and stockier in build than the average person, it is particularly significant that a program emphasizing dietary controls and exercise may be helpful in reducing the incidence of diabetes among this population [17]. Although there are no specific recommendations regarding screening for diabetes in individuals with Down syndrome, it may be reasonable to screen these patients for this disease. They should also be counseled about diet, exercise, obesity, smoking, and alcohol use [28].

Cardiovascular Problems

In some respects, there appears to be good news for adults with DD in the area of cardiovascular problems. Although individuals with DD have a higher rate of congenital heart defects and may have complications that persist into adulthood, the risk of additional cardiovascular problems have been found to be no higher for individuals with DD than they are for the general population [54; 55]. Additionally, women with Down syndrome have been found to be less likely to show insulin resistance syndrome, a neuroendocrine disorder that underlies atherosclerosis and diabetes [53; 56]. Both men and women with Down syndrome have fewer arteriosclerotic risk factors than a similar group of individuals without Down syndrome [56].

A significant and demonstrated factor in the reduced risk for cardiovascular disease for these individuals is lower dietary fat consumption and frequent physical exercise. Those who adopted these habits were one-third less likely to have insulin resistance syndrome and abdominal obesity compared to those who participated in less frequent exercise or who consumed higher intakes of dietary fat [53]. This is important information for caregivers and healthcare providers to adults with DD. Appropriate diet and lifestyle, with lower fat intake and regular exercise, is significant in reducing the risk for both diabetes and cardiovascular conditions. Encouraging participation in sporting events, such as the Special Olympics, may be beneficial for DD patients' health in addition to the benefits of establishing a supportive peer group.

Osteoporosis

Lower bone density and resulting osteoporosis have been found to be common among people with DD [18; 57; 58; 59]. A study of men institutionalized with DD found that 34% had ultrasound index values two standard deviations below an age-matched control group. Additionally, 51% had values more than two standard deviations below the reference group, demonstrating a very high occurrence of low bone mineral density [57]. A study of institutionalized postmenopausal women with DD found that 82% were at high risk for osteoporosis, with a severe decrease in bone mineral density [58]. This is due to multiple factors, including Down syndrome, smaller body size, endocrine abnormalities, reduced physical activity, reduced muscle strength, use of certain medications, and in women/girls, high phosphate levels [29; 47; 60].

Low vitamin D levels have also been reported in both men and women [60]. However, it is unclear if low vitamin D levels are associated with dietary issues or if they may result from other factors. Additionally, the effects of vitamin D on bone health have been difficult to separate from the associated effects of dietary calcium [61]. Certain anticonvulsant medications are known to affect the absorption of vitamin D, and this may also be a factor [62].

Bone density measurement may be difficult because individuals with DD may not be able to achieve the positioning needed for a central dual photon x-ray absorptiometry (DEXA) measurement or may not be able to lie still for the time it takes to do a scan. In addition, differences in bone and body size, shorter stature, anatomical deformities, and behavioral alterations may prevent accurate measurements. Calcaneal (heel) DEXA, peripheral DEXA of the finger, photon absorptiometry of the lumbar sacral spine, central DEXA of the femur, and ultrasound are testing options that may be useful alternatives in these situations. These options have shown good correlation with a central DEXA measurement but are not generally used to monitor treatment [47; 63].

EVIDENCE-BASED PRACTICE RECOMMENDATION

According to the College of Family Physicians of Canada, osteoporosis and osteoporotic fractures are more prevalent and occur at a younger age among people with intellectual/developmental disabilities than among those in the general population. Therefore, they recommend screening both male and female patients for osteoporosis starting in early adulthood. Clinicians should seek advice from a radiologist regarding alternative methods to assess risk of fragility fractures if the patient cannot be assessed using the usual nuclear bone mineral density test, such as by assessing the patient's forearm only.

(https://www.cfp.ca/content/64/4/254. Last accessed June 10, 2022.)

Strength of Recommendation: Strong recommendation

From a nursing standpoint, the concern should be for the high risk of falls and subsequent fractures and complications. A study of 268 elderly adults with DD determined that falls and injuries were higher in those who were 70 years of age, ambulatory, on antipsychotic medication, had suboptimal seizure control, and were exhibiting more destructive behaviors. Procedures that may help minimize the risk of falls in ambulatory patients include corrective eyewear, suitable shoes, maintenance of good lighting, and a safe environment. Screening for risk of falls may be different in the elderly population with disabilities compared with the normal elderly population [63].

Case Study

Ms. M, Ms. J, Ms. A, and Ms. C are four women, all older than 50 years of age, who reside in a group home setting. All of the women participate in a sheltered workshop during the week and are active participants in a variety of activities offered to the residents in their group home. Two of the women, Ms. J and Ms. C, have family who live in the area, and they often spend weekends and holidays at a family member's home. Their primary care physician sees all four women for yearly physicals, and they receive mammograms and Pap tests on a yearly basis. All four women receive supplemental calcium with vitamin D (600 mg twice daily). This year during their physicals, their physician refers all four women for a bone density study. Based on the results of the studies, both Ms. M and Ms. C are placed on raloxifene (Evista), 60 mg daily. The reports of the studies are forwarded to the nurse consultant. Ms. M's report shows mild osteopenia in her spinal column. Ms. C's report shows significant osteoporosis in both hips and femur. It also shows osteopenia in the spinal column, indicating a significant risk for fracture.

Ms. C is 60 years of age, with cerebral palsy. She ambulates with a wheeled walker. She requires a rocker knife and fork to feed herself but does remain substantially independent in her group home setting. After reading the report, the nurse consultant advises Ms. C's case manager of the findings and recommends discussing the results with Ms. C's sister, who is her advocate, and alerting the direct care staff members to the fall risk. The multidisciplinary team also decides, with Ms. C and her sister's agreement, to place half side rails on Ms. C's bed. Until this time, Ms. C has been very slowly walking the block between the workshop and her home twice a day. This is becoming increasingly difficult for her, and she frequently cries with pain, complaining of feeling too tired for activities after returning home. It is decided to transport her via wheelchair to and from the workshop, with her continuing to use her walker for all other ambulation. She is included in a weekly yoga group and a daily stretching exercise group at the workshop to help increase her agility and muscle strength.

MENTAL HEALTH

Individuals with mild-to-moderate developmental disabilities are likely to also have a diagnosis of mental illness. However, actual estimates of the frequency of occurrence of psychiatric diagnosis among those with DD vary [64; 65]. Estimates of psychiatric diagnoses among individuals with intellectual disability range from 30% to 35% and suggest that some mental health conditions are more common among individuals with intellectual disability than in the general population [66; 67; 68]. There has been limited research studying mental health problems among adults with DD and even less in terms of treatment. There is little in the literature on assessment, diagnosis, and treatment of mental illness in this population; however, there is a growing interest in therapies that can help control challenging behaviors in the developmentally disabled population [67]. Accurate prevalence estimates are necessary to ensure the availability of appropriate treatment services [68]. Behavior problems are often assumed to be an outcome of the disability and not pursued beyond medicating to try to suppress behaviors [69; 70].

MENTAL HEALTH PROBLEMS ASSOCIATED WITH PARTICULAR SYNDROMES

Syndrome	Possible Mental Health Problems
Prader-Willi syndrome	Obsessive-compulsive behaviors Self-injurious behaviors Obsession with food
Fragile X syndrome	Attention deficit disorder Obsessive-compulsive behaviors Poor sensory integration
Down syndrome	Obsessive-compulsive behaviors Attention deficit disorder Autism Depression Early-onset dementia
Autism spectrum disorder	Obsessive-compulsive behaviors Ritualistic behaviors Poor social skills
Williams syndrome	Hyperactivity Extreme uninhibited behavior Obsessive behaviors Somatic complaints Extremes of moods
Fetal alcohol syndrome	Attention deficit/hyperactivity disorder Impulsivity Depression Panic disorder

Source: [69] *Table 3*

ASSESSMENT

As with physical problems, mental health issues may be associated with particular conditions of developmental disability. Mental health problems may also be acquired as a result of trauma or psychologic events occurring in the life of the individual with DD [71]. Obsessive-compulsive disorders, impulse control disorders, attention deficit disorders, and autism are a few of the psychiatric conditions that tend to occur with certain developmental disabilities. Post-traumatic stress disorder (PTSD) may result from experiences of abuse and trauma in the lives of adults with DD. Depression is often related to relationship issues, lack of social supports, or environmental changes and/or communication difficulties that the individual with DD is experiencing. It is also important to remember that patients with DD are at increased risk for maltreatment, and this can lead to psychiatric disorders such as depression. ***Table 3*** illustrates specific mental health issues that are commonplace with certain developmental disabilities [69]. There is some evidence that depression and early-onset dementia are more common in patients with Down syndrome [17; 28; 69].

Assessment of mental health issues in those with DD is a complex process [28; 69; 72]. Although a number of mental health professionals may be involved in the assessment and treatment process, nurses are important contributors to patient care because they are with the patient 24 hours a day and can recognize changes in the patient that may be associated with mental health problems or other causes.

At the beginning of the assessment process, changes are significant and should be explored for possible cause. Behavior changes, including injury to self, impulsive behaviors, anger outbursts, and changes in sleep patterns, eating habits, and level of participation in activities, may all be signs of a mental health problem [29; 69]. Other mental health issues may arise when they interfere with placement choices. Particularly, obsessive-compulsive disorder, impulse control disorder, and attention deficit disorder may present more of a problem in some settings than in others and, when left untreated, may lead to more challenging behaviors [29]. Also, these behaviors may seriously interfere with an individual's ability to be successful in the least restrictive environment.

There are some keys to being able to successfully assess mental status in individuals with DD. Again, nurses may be the ideal healthcare professional to do this because they are most likely to have established rapport with the patient and will be able to assess all aspects of the situation. Most significantly, nurses should be able to recognize nonverbal signs and obtain information in a nonthreatening manner. Redirecting in a nonconfrontational manner and reinforcing appropriate social responses will help [70; 101].

It is always possible that a new problem behavior or the worsening of a pre-existing behavior is caused by more than one factor, and assessment data should be collected and reviewed to narrow the problem. Physical causes should always be ruled out prior to deciding to start treatment for a psychiatric problem [29]. Pain issues, side effects or toxicity from medications, hypothyroidism, hormonal fluctuations, inflammatory processes, and infections may all present with associated behavior changes [69; 70].

A structured mental status assessment that includes all of the following areas will be most successful in collecting important data for psychiatric evaluation [70]:

- Judgment of the individual's perception of events, aggression, thoughts of suicide, appearance, and response to recent life events
- Orientation to surroundings and location
- Memory, tested with questions related to names of caregivers, events from the previous day, etc.
- Affect and attitude, evaluated in much the same manner as they are in any mental status exam. Some data, such as changes in activity level, sleep patterns, and eating habits, should be collected from caregivers, depending on the level of impairment experienced by the individual.
- Cognition, as determined by the ability to remain focused, speech patterns and verbalizations, and behaviors that indicate paranoia, delusions, or hallucinations

Assessment should also include information on family history because this is as significant with DD as it is in the general population [69; 73]. Bipolar disorder, schizophrenia, and some anxiety disorders are prevalent in some families. This aspect should not be overlooked in obtaining data. If it is determined that a psychiatric diagnosis is applicable and treatment is begun, periodic mental status assessments should be completed to determine progress and evaluate the need for continued treatment.

Depression and Dementia

Alzheimer disease is the most common form of dementia. Individuals with Down syndrome develop a clinical syndrome of dementia that is nearly identical to the characteristics of Alzheimer disease described in individuals without Down syndrome. The main difference is the early age of onset (i.e., late 40s or early 50s) in individuals with Down syndrome [17; 74; 75]. It is not clear why there is an increased likelihood of dementia in this population, but it is clear that the plaque and tangle formations found in the brain of individuals with Alzheimer-type dementia are sometimes found in the brains of individuals with developmental disorders. Additionally, there is an increase in frequency as the person with DD ages [74; 75]. Epidemiologic and brain imaging studies of patients with Alzheimer disease and without Down syndrome have led to observations that patients with limited education or diminished baseline cognitive abilities may be at increased risk for Alzheimer disease. These data have led to the cognitive reserve hypothesis, which suggests that patients with better baseline cognitive abilities can tolerate more Alzheimer disease pathology and neuronal loss than patients with worse baseline cognitive abilities. Because most patients with Down syndrome have developmental disabilities and limited baseline cognitive ability, the cognitive reserve hypothesis would suggest that patients with Down syndrome are at increased risk of developing Alzheimer disease [75].

In some cases, the signs of dementia are associated with the use of neuroleptic medications, hypothyroidism, or depression. For a diagnosis of dementia to be made, the individual must be found to be functioning at a cognitive level below their baseline and the decline must be progressive. Nurses can make a significant contribution in helping to assess an individual for dementia because they are most likely to observe the individual frequently and be able to provide a clearer picture of changes from the baseline level of functioning. Additional studies of individuals with Down syndrome residing in communities have shown a lower occurrence of dementia than in previous studies of institutionalized populations. It is possible that the more active lifestyle of community residents has helped reduce their chances of having early onset dementia [74].

EVIDENCE-BASED PRACTICE RECOMMENDATION

Dementia is more prevalent among adults with intellectual/developmental disabilities compared with the general population, with a statistically significantly increased risk in adults with Down syndrome and at an earlier age. For patients at risk of dementia, the College of Family Physicians of Canada recommends referring to a psychologist for a baseline assessment of cognitive, adaptive, and communicative functioning after 40 years of age and at 30 years of age for people with Down syndrome.

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Level of Evidence: Moderate recommendation

Depression is a persistent alteration in mood, behavior, and cognition that has biologic and psychologic underpinnings and results in functional decline. It often goes unrecognized and untreated, leading to poor quality of life, increased medical comorbidity, decreased ability to live independently, caregiver burden, and heightened mortality [76]. Despite widespread acceptance that depression can occur in adults with intellectual disability, the difficulties encountered when assessing and diagnosing depression in this population may hamper the individual clinician and make selecting appropriate treatment problematic [77]. Depression may be missed when signs of depression are attributed to other causes or to the disability itself. Although new tools have emerged, there is as yet no gold standard diagnostic tool for assessing depression in this population [72; 78; 79].

TREATMENT OPTIONS

Tremendous progress has been made in the treatment of mental illness. A wide variety of medications have become available, many with significantly fewer side effects and more precise methods of action than their predecessors. This has resulted in improved results in the treatment of major depression, anxiety disorders, schizophrenia, and bipolar disorder among the general population. However, this may not always be the case in the treatment of individuals with DD who also struggle with mental illness.

Individuals with DD are one of the most medicated groups in society [80]. However, many individuals with DD who receive psychotropic medications have been inappropriately diagnosed. One of the primary reasons for the use of these medications is aberrant behaviors. Findings of a 10-year review of the literature indicate that the majority of studies that have been done in this area contain serious flaws; medications were often given for inappropriate diagnoses, results were not properly evaluated, and there were instances of medications being used as chemical restraints [81]. Prescribing practices for individuals with DD who are not institutionalized also have not significantly improved. For example, regardless of location, the most frequent predictor of psychotropic medication use has been problem behavior rather than a specific psychiatric diagnosis. Lack of knowledge among caregivers making referrals for psychiatric problems and lack of knowledge among general practice physicians who are most likely to be providing care have also been cited as contributing to this problem [80].

The presence of psychiatric disorders among individuals with DD requires clinicians to adjust and modify standard mental health assessment and treatment planning. As previously mentioned, assessment should include the input of a multidisciplinary team, with treatment planning and implementation focused on long-term management of both disorders. Emergency interventions, specialized respite services, hospitalization, and other transition services may be needed due to the commonplace recurrence of mental disorders and the presence of ongoing risk and vulnerability factors for mental disorders. However, the quality, availability, and access to these services vary considerably and are affected by a variety of factors (e.g., political, economic, sociocultural) that impact the willingness to use services and the distribution of qualified, trained professionals able to manage individuals with dual diagnoses [82].

Medications

Psychotropic drugs may be of great benefit if they are given for specific diagnoses and symptoms. Drugs of most benefit in psychiatric care of individuals with DD are antidepressants, mood stabilizers, and antipsychotic medications [69]. Antidepressants are widely used in the general population, including in adolescents and children, for the treatment of depression, anxiety disorders, obsessive-compulsive disorders, and PTSD. Although the possibility of side effects is not entirely absent, consideration should be given to the damaging effects of untreated depression, and a balance should be achieved.

Mood stabilizers include lithium, valproic acid, lamotrigine, oxcarbazepine, and carbamazepine. With the exception of lithium, all of these drugs are also used for seizure control, and a dual benefit may be achieved in some individuals with DD [84]. These drugs are also used to treat bipolar disorder, and in individuals with DD who have a family history of bipolar disorder, it is appropriate to assess for signs of mood instability and treat accordingly [84]. Although there is limited data, clinical experience and some research indicate success in reducing aggression and self-injury in those with DD with the use of valproic acid [81].

Atypical (i.e., second-generation) antipsychotics were developed in the 1990s and are often used because they are thought to have fewer side effects and better efficacy than their predecessors [84]. They include risperidone, quetiapine, olanzapine, ziprasidone, aripiprazole, lurasidone, and paliperidone and are used to treat schizophrenia, severe anxiety, and aggression. These drugs are now more accepted than first-generation antipsychotics, but there is still a potential for extrapyramidal symptoms and weight gain [40; 84]. It is important to note that the FDA has issued a Public Health Advisory for atypical antipsychotic medications because it has been determined that death rates are higher for elderly people with dementia when taking these medications. Antipsychotic medications are not FDA-approved for the treatment of behavioral disorders in patients with dementia [84].

In some individuals with DD who are demonstrating psychotic thinking processes and are paranoid, delusional, and/or hallucinating, the use of antipsychotics is indicated. In situations of extreme aggression or self-injurious behavior, they may also be indicated. It is important to note that while aggressive challenging behavior is frequently reported in adults with intellectual disability and often treated with antipsychotic drugs, there is no adequate evidence to support this practice. Antipsychotic drugs should no longer be regarded as an acceptable routine treatment for aggressive challenging behavior in people with intellectual disability [85].

Nursing responsibilities in the use of psychotropic medications are to provide accurate assessment information and monitor for side effects and interactions with other medications. Nurses should ensure that all direct care staff members are aware when a new medication is prescribed and advise them of what to watch for. All individuals receiving antipsychotics should be regularly tested for movement disorders to provide objective data [84]. Because seizure disorders occur so frequently in individuals with DD, nurses should be particularly alert for an advent of seizure or an increase in frequency when psychotropic medications are being used [40].

Case Study

Mr. M is 42 years of age and resides in a group home, where he attends a sheltered workshop. He has been diagnosed with a moderate developmental disorder. Other diagnoses include seizure disorder, hypothyroidism, and hypercholesterolemia. He enjoys a variety of activities, including simple puzzles, baseball games, and going out to eat. His seizures are fairly well controlled with valproic acid 1,000 mg twice daily and topiramate 100 mg twice daily. He seizures at five- to six-week intervals and is often confused after seizures. Generally, he is cooperative with staff members' requests, but in the past two months, he has had five incidents of swearing and striking out at other residents. On two occasions, he has been physically aggressive with staff members.

After a meeting with the case manager, Mr. M's mother, the workshop supervisor, the nurse consultant, and Mr. M, it is decided to ask all staff members to observe Mr. M closely over the next two weeks to attempt to identify the source of his aggression. At the meeting, his mother reports that she has observed Mr. M talking to images on his television. When the group meets again two weeks later, the case manager has collected behavior observation sheets that indicate the activities Mr. M was engaging in at half-hour intervals. It is apparent that he is spending more time in his room. He has been observed on six occasions swearing at the television. There were also four incidents of physical aggression toward staff members and other residents. His mother reports that he seems very focused on characters on a reality show and talks about them as if he knows them. She also reports that he becomes quite angry while talking about the characters. It is decided that a psychiatric consult was necessary.

The psychiatrist evaluates Mr. M. When asked about the television programs, he is reticent to discuss them and reports to the psychiatrist, "They'll come after me." The psychiatrist concludes that Mr. M is experiencing thought insertion and delusions associated with his inability to correctly interpret reality television. This is leading to paranoia and physical aggression. The psychiatrist recommends quetiapine 50 mg twice daily and limiting television watching.

The case manager seeks approval from the facility's human rights committee for the medication and for a right restriction to limit television viewing. The committee, which includes Mr. M's mother, agrees, and the quetiapine is started. Mr. M's behavior plan is amended to identify efforts by the staff members to engage him in other activities and to encourage television watching in the day area. Fortunately, baseball season is starting, and it is possible to engage Mr. M and several other residents in watching baseball games.

After three weeks, Mr. M is spending more time with his peers, and there have been no further incidence of aggression. He appears to be tolerating the quetiapine well, and there has been no increase in seizures. After two months, the quetiapine is reduced to 50 mg at bedtime, and Mr. M continues to do well.

Nonpharmacologic Treatment

There is beginning to be more consideration of nonpharmacologic treatment for mental health disorders among adults with DD. This is probably due in part to the increase in individuals with DD living in community settings and, in many cases, receiving care at community mental health centers. Unfortunately, there is a lack of specially trained mental healthcare providers available to meet the needs of this population. Advanced practice psychiatric nurses are a group who has the ability to provide services and advocacy for individuals with DD and their families [83; 86]. This has been the experience of the author in providing psychiatric nursing consultation to residential care facilities for adults with DD.

Behavior Modification

Behavior modification is based on the work of Skinner and is familiar to those who have taken a basic psychology course. The principle of behavior modification is based on the theory that all behavior is in response to positive and negative reinforcement and can be modified based on that theory. An outgrowth of Skinner's work was the establishment of behavior modification programs to treat the chronically mentally ill and individuals with DD [87]. In the 1950s, when these programs were put into place in institutional settings, considerable progress was made in the area of training institutionalized populations on basic skills. After a time, however, ethical and legal concerns arose about the use of negative reinforcement strategies, and many programs were abandoned [69]. However, there is still some value in the use of behavior modification, such as using a reward system to reinforce a desired behavior. For example, token economies, where the individual receives a token for a positive behavior and the token is later cashed in for a desired reward, have been successful in encouraging desired behaviors. If these interventions are included in a treatment plan and appropriate institutional approval is obtained, they can be very beneficial. The following is an example of the use of behavior modification to solve a health problem for a particular individual.

Case Study

Ms. J is a woman with mild developmental disability, diagnosed with type 2 diabetes, recurrent major depression, and PTSD. She lives in a residential facility. Her diabetes is treated with some success with oral agents, although she is noncompliant with diet restrictions. Her recurrent depression and PTSD are treated with an antidepressant and a mood stabilizer. Ms. J's weight remains around 185 lbs, and she has fat folds below her breasts and in the groin area. Direct care staff members report that Ms. J does not shower daily and often goes five to six days without a shower. The nursing staff notes when doing weekly skin audits that Ms. J has excoriated areas in the fat folds and she is complaining of discomfort. The nursing staff has explained to Ms. J the need to shower and dry the area well each day and that topical medication will then be applied to heal the area. Ms. J continues to refuse to shower regularly, and it is determined that it is a necessity for her own well-being that she do so. The case manager discusses this with Ms. J and sets up a program in which she will receive a portion of her weekly allowance on a daily basis, but only after she has showered for the day and allowed the nurse to apply the medication. Ms. J and her advocate agree to this arrangement, and the information is shared with the facilities human rights committee to obtain permission for a rights restriction. After a few weeks, the skin areas begin to heal, and Ms. J is complying with showers on most days. It is determined by the multidisciplinary team to continue the behavior modification strategy with a review on a quarterly basis by the human rights committee.

Cognitive Therapy

Cognitive therapy has been well-received in psychiatric care as an effective treatment for depression and anxiety. The principle of cognitive therapy is to help the individual change their negative self-view, thus improving his or her self-esteem and coping skills. Emphasis is placed on changing negative thinking patterns rather than just changing behavior [69; 87]. Cognitive therapy focuses on learning new behaviors by using techniques introduced by the therapist [88; 99]. Cognitive behavioral therapy has been used successfully with DD adults, and emerging studies, specifically on dialectical behavior therapy, have shown promise in effectively treating individuals with DD [67; 69; 88; 100]. Role-playing, modeling, and homework assignments are some of the strategies used to initiate changes in thought and behavior.

QUALITY CARE

Nursing has a major role in providing care for individuals with DD in all settings. Three important aspects of the nursing role are education, prevention, and support. Services are provided in care coordination, direct nursing care, health promotion, and health restoration. Nurses may also function in the role of case manager and be responsible for coordination of care provided by consultants and other members of the multidisciplinary team. In some settings, another provider will be the case manager and the nurse then has the responsibility of interpreting healthcare needs and educating other members of the team in those areas.

FAMILY-CENTERED CARE

Families are generally very involved in the care of a family member with a developmental disability. Often, a family member will serve as guardian or advocate for their relative. Nurses should work collaboratively with family members to promote health and manage healthcare needs. There is often a significant need for education to help family members understand the purpose for diagnostic tests, medications, and other healthcare procedures. Providing caregivers in advance with a referral sheet documenting the information expected for each office visit may be helpful [29]. It is important in these circumstances to be sensitive to the family's value system and its view of quality of life for its family member.

Local chapters of the AAIDD may serve as helpful resources for nurses who work with these families. The AAIDD includes professionals, family members, and advocates for individuals with DD. Its mission is to promote progressive policies, sound research, effective practices, and universal human rights for people with intellectual and developmental disabilities [2].

Recognizing the value of the family in providing for an individual and utilizing the strengths and diversity of each family are tasks for nursing and the entire team involved in the care of the DD individual. In many instances, the nurse will be well accepted by the family simply because nurses are seen by many as knowledgeable caregivers and liaisons with the rest of the healthcare system. The basis of family-centered care is a partnership between the family and the professionals.

COMMUNITY

Knowledge of community resources is essential in providing adequate care for individuals with DD. Although this may vary from state to state, there are many resources available. Passage of the Americans with Disabilities Act has done a great deal to make public resources more accessible. Nurses who work with the developmentally disabled population should know what resources are available in their immediate area as well as statewide.

Serving as an advocate for the disabled has long been a part of nursing [89]. As deinstitutionalization has occurred, more individuals with severe developmental disabilities have come to reside in community settings. Care for these individuals often requires supervision by a nurse. While most nursing care has, in the past, been delivered within an institution, care is now more commonly delivered within the community. While this may require a different approach, many of the goals remain the same, including creating an environment that supports good health practices.

Health promotion enables people with DD to achieve their health goals by ensuring they have equal opportunities and access to information, are in supportive environments, and have the opportunity to acquire the life skills needed to make healthy choices. This requires coordinated efforts from all interested groups, including individuals, families, and communities. Community-based health promotion emphasizes community participation as well as empowerment of individual community members.

When individuals with DD have been empowered and are able to participate in community-based health promotion activities, health becomes a resource for success in everyday life [90].

Most community resources are designed for young adults with DD. An example of this is the sheltered workshop, which provides work as part of the lifestyle for disabled individuals. However, as this population approaches retirement, what resources will be available for those who have not been part of a sheltered workshop? Community-based services should continue to be developed to meet the needs of this group as well as the rest of the aging population [91]. Some programs for adults with DD are beginning to look at this and plan for the older person with DD, but there is still much to be done in this area.

People with intellectual disabilities also require access to compassionate, quality, and effective palliative and end-of-life care when facing serious, life-limiting illness. A survey of 22 hospice and palliative care providers, 50 group home/community living sponsors, and 5 state-run developmental centers was designed to assess the provision of hospice and palliative care services to this population. The challenges to providing services cited by survey participants included: low levels of knowledge about palliative care among residential providers; need for knowledge about people with intellectual disabilities among hospice providers; communication difficulties; and cost concerns regarding reimbursement, staffing, and training [92]. These challenges and others (e.g., difficulties in assessment and patient fear) have been cited by other studies and support the need to increase awareness and knowledge about intellectual disabilities, promote hospice outreach to residential providers, and develop innovative services and policies that address the challenges in caring for this population [92; 93].

STANDARDS OF CARE

Advances in medicine, including improved health practices and medical care, have resulted in an increase in the number of DD individuals who survive into adulthood. As this population ages, additional needs must be met. These needs require a tailored approach from the nursing profession. The American Nurses Association (ANA) nursing standards provide specific direction on the scope of practice and a description of nursing of individuals with DD [94]. An important aspect of these standards is the emphasis on ethical principles in working with a dependent population. Society has a moral obligation to protect and provide for this group of people. Nurses are in a unique position to advocate for and protect these individuals.

Healthcare providers should work together with parents, other relatives, and guardians to make the best decisions regarding quality of life and health care. Generally, each individual will have someone appointed to either serve as a guardian or to act as an advocate in making decisions regarding health care. This will vary from state to state, and nurses should be familiar with the requirements in the state in which they practice. The ANA nursing standards can serve as a helpful resource [94].

There are a variety of state and federal laws that relate to institutional care provided for individuals with DD. Some are similar to regulations for nursing homes, but there is some variation. Nurses working exclusively with adults with DD should be aware of laws and regulations that apply to the group with which they are involved.

CONCLUSION

Nursing care of the adults with DD has changed dramatically as these individuals have moved out of institutions and into community settings. In most cases, people with DD have been integrated into the community at large and may be seen in any healthcare setting. Unfortunately, healthcare providers have very little training in their original program of education and very little continuing education in working with adults with DD [11; 17; 66]. This means that this population is often underserved and does not receive the preventive care, health maintenance, and treatments that would improve the quality of their life.

Efforts are now being made in the direction of better educating the healthcare community, both for the benefit of individual practitioners as well as the developmentally disabled population and their families. Quality care and access to care are issues of significance to everyone, and no one group should be excluded or provided a lower standard of care. It is important for those of us in the healthcare field to make an effort to educate ourselves and reach out to those with DD, thus ensuring they receive the best health care possible.

RESOURCES

Administration on Intellectual and Developmental Disabilities (AIDD)
https://acl.gov/about-acl/administration-disabilities

American Association on Intellectual and Developmental Disabilities (AAIDD)
https://www.aaidd.org
(202) 387-1968

National Association of Councils on Developmental Disabilities (NACDD)
https://www.nacdd.org
(202) 506-5813

National Association for the Dually Diagnosed (NADD)
http://thenadd.org
(845) 331-4336

National Down Syndrome Society (NDSS)
https://www.ndss.org
(800) 221-4602

The President's Committee for People with Intellectual Disabilities
https://acl.gov/programs/empowering-advocacy/presidents-committee-people

Implicit Bias in Health Care

The role of implicit biases on healthcare outcomes has become a concern, as there is some evidence that implicit biases contribute to health disparities, professionals' attitudes toward and interactions with patients, quality of care, diagnoses, and treatment decisions. This may produce differences in help-seeking, diagnoses, and ultimately treatments and interventions. Implicit biases may also unwittingly produce professional behaviors, attitudes, and interactions that reduce patients' trust and comfort with their provider, leading to earlier termination of visits and/or reduced adherence and follow-up. Disadvantaged groups are marginalized in the healthcare system and vulnerable on multiple levels; health professionals' implicit biases can further exacerbate these existing disadvantages.

Interventions or strategies designed to reduce implicit bias may be categorized as change-based or control-based. Change-based interventions focus on reducing or changing cognitive associations underlying implicit biases. These interventions might include challenging stereotypes. Conversely, control-based interventions involve reducing the effects of the implicit bias on the individual's behaviors. These strategies include increasing awareness of biased thoughts and responses. The two types of interventions are not mutually exclusive and may be used synergistically.

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