

Primary Care for People with Disabilities

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Abstract

People with disabilities are a unique population. Although there have been great advances in their care, access to reliable and consistent primary health care remains a difficult issue for many of these patients after discharge from medical rehabilitation units. Many of these health care needs are not unique to this patient population, but become compounded or exacerbated in people with disabilities. The effects of physical impairments on these patients' health need to be recognized. Specific attention must be paid to prevent the occurrence of secondary disabilities, which can drastically affect their independence. Ultimately, proper attention to the health care needs of people with disabilities will result in greater independence and improved health among this population. **Key Words:** Primary care, disability, preventive health, health maintenance.

Introduction

THE SPECIALTY OF PHYSICAL MEDICINE and Rehabilitation (PM&R) focuses on the health care needs and restoration of function, of people with physical and cognitive impairments. Since the beginning of the 20th century, and especially since World War II, an increasing number of persons with severe impairments have been living longer.

Various advances in health care technologies since the 1930s and 1940s have increased the survival rates of persons with disabilities. Important developments have occurred in the area of antibiotics, acute trauma care systems (especially as a result of WWII), respiratory support systems (negative pressure body respiration, then positive pressure systems), and finally, advances in cardiopulmonary resuscitation methods. Rehabilitation programs began to develop during this period, as a response to the increasing number of

individuals with severe disabilities who were living longer and more productive lives despite their permanent impairments.

Concomitantly, societal attitudes have changed toward people with disabilities. These changing attitudes ultimately resulted in the passage of the Americans with Disabilities Act, which entitles all persons with disabilities to fair and equal access to environment services and opportunities.

Despite great strides over the past half century, there are still many barriers for the person with a disability. Access to a reliable, ongoing source of primary health care remains one of the major unresolved issues for people with disabilities who are discharged from medical rehabilitation units (1).

Unique Issues for People with Disabilities

Many of the medical conditions encountered by people without disabilities are also relevant to those with disabilities. In addition, the wide variety of impairments present differently in individuals with disabilities because of varying pathophysiologies, co-morbidities, and functional consequences. However, persons with disabilities may be more vulnerable to common health condi-

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tions, and they may present differently or require a more lengthy therapeutic regime that takes into account their underlying impairment and functional limitations.

DeJong (2) points out six ways in which the ongoing health care needs of persons with a disability are different from those of the general population:

- The narrow margin of health, which necessitates careful monitoring in order to avoid medical problems. This is relevant to certain health conditions shared by people without a disability (i.e., upper respiratory tract infections, pneumonia), but especially relates to conditions found in persons with disabilities (e.g., pressure sores). These impairments and functional limitations result in a thinner margin of health, leading to increased medical problems.
- Limited availability of “insurance” or prepaid coverage for health care and preventative medicine.
- The risk of acquiring a chronic health condition at an earlier age than is usual in the general population (e.g., coronary artery disease in the individual whose mobility is limited; or in whom a lack of aerobic exercise leads to increased weight gain and an earlier onset of type II diabetes).
- Onset of a new health condition, which leads to a secondary functional loss, with resulting significant physical limitations and increased dependence.
- A more complicated and prolonged course of treatment before restoration of their previous functional status.
- The need for durable medical equipment devices and other assistive technologies which require detailed knowledge by both the prescriber and patient.

Identifying the Problem

In 1988, The American Congress of Rehabilitation Medicine adopted a white paper on the post-rehabilitation health care needs of people with disabilities. It was updated in 1993 (1). Its main point is that people with disabilities are not well served by the health care system after discharge from medical rehabilitation units. This lack of access to primary care then leads to recurrent but often preventable health problems.

These post-discharge health problems lead in turn to increased rehospitalizations compared to the general population, often approaching 40% in the first year. The two leading causes, urinary tract infections and pressure sores, are preventable (3).

Aging with a disability presents its own unique difficulties. The health care needs increase markedly in this population. They are living long enough to experience the chronic health problems faced by the able bodied (e.g., osteoporosis and cardiovascular disease). But these conditions tend to surface earlier and lead to worse consequences for persons with physical disabilities. These new chronic conditions tend to aggravate existing functional losses and then compromise a person’s ability to work and live independently.

The provision of long-term services in the form of personal assistance remains a very important issue for a person who requires assistance with personal care. Nosek (4) showed that inadequate personal assistance led to extended hospital stay and inability to maintain good physical and mental health.

As disproportionately high users of health care services, people with disabilities have been grossly affected by the current trends in health care reform. Health insurance continues to become less accessible, less affordable, and less adequate in its coverage for a population of people who require it most.

Finally, access to primary care is an important issue for persons with disabilities particularly since physical barriers may be present. More time and effort may be required to attend to the problems presented by those with disabilities. Moreover, the staff may not know how to safely handle the mobility-impaired patient.

Health Promotion Needs of Persons with Disabilities

A permanent disabling disorder or a chronic illness leads to additional specific needs. These include prevention of secondary disabilities and management of the unique issues of aging with a disability. In addition, these patients need standard health maintenance and wellness promotion. Even though there is no consensus among The American College of Physicians (ACP), The Canadian Task Force (CTF), and the U.S. Preventive Services Task Force (USTF), most recommendations of the expert panels call for selective screening, counseling, and prophylaxis (5).

Wellness Promotion and Health Maintenance

It is important to monitor those factors which could lead to decreased independence in persons with disabilities. Nutritional counseling, to help them maintain a desirable weight and limit fat and cholesterol intake, is important. Height on initial visit and weight at least every year should be obtained in order to calculate the patient's body mass index (BMI, kg/m²). Good dental health should be encouraged. Screening for glaucoma and periodic refraction is necessary, to limit worsening of functional status secondary to deteriorating vision. Maintaining good cardiovascular fitness is paramount in the mobility-impaired patient. Blood pressure should be checked at every visit and a periodic ECG should be obtained for all patients over the age of 40 with risk factors for coronary artery disease, or those who plan on starting an exercise program after a prolonged period of immobility. Exercise stress testing is not recommended routinely, but should be considered for the patient over age 40 who has risk factors for coronary artery disease. Obviously, the patient's level of mobility will dictate the type of stress test (i.e., treadmill vs. chemical). Exercise consistent with the patient's condition should be encouraged. A cognitive and functional assessment of all elderly patients should be performed; it should include screening for depression.

The selective use of laboratory screening tests is also recommended, bearing in mind that recommendations put forth by the three expert panels may differ (5). Each patient encounter should be individualized. A hematocrit is not routine, but should be obtained for low socioeconomic and institutionalized elderly patients. Obtain a urine analysis for patients over 60 years old and all diabetic patients. Fasting plasma glucose is not routinely recommended except in those with a family history of diabetes, a history of gestational diabetes or obesity. A serum cholesterol should be obtained at least by age 30 and then every five years. The ACP and USTF recommend thyroid function testing in women with nonspecific symptoms after the age of 50 and 60, respectively. HIV serologic screening is necessary in all patients with high risk behavior or who received blood transfusions between the years 1978 and 1985. Syphilis serologic screening should be done for all patients with high risk sexual behavior. Routine prostate specific antigen is not recommended by any of the three expert panels. Further use of blood tests is decided based on the history and physical.

Tuberculin skin testing is needed for all patients exposed to tuberculosis, those with HIV and those taking high dose steroids. A screening chest x-ray for lung cancer is not recommended by any panel. Bone density analysis should be considered in perimenopausal women, those with early menopause and slender women. A yearly routine mammogram is recommended for all women from age 50, and in those after the age of 35 with a premenopausal first-degree relative who had breast cancer. Routine cervical cytologic screening is routine for all women after the age of 20 or at the onset of sexual activity.

Stool for occult blood should be obtained after the age of 50 from all patients, and after 40 from those with a first-degree relative with colon cancer or history of inflammatory bowel disease. Routine sigmoidoscopy is recommended by the ACP after the age of 50 or after the age of 40 for those with a first-degree relative with colon cancer, a history of inflammatory bowel disease, or endometrial, breast, or ovarian cancer. If there is a first-degree relative with colon cancer, a history of ulcerative colitis for more than 10 years, adenomatous polyps, or familial polyposis, a colonoscopy should be obtained.

Vaccinations and Chemoprophylaxis in Adults

An updated vaccination record should be maintained in each patient's chart. The role that a patient's disability plays in altering the time at which the patient should receive a vaccination has not been fully researched. The recommendations were reviewed by *The New England Journal of Medicine* (6) and the *Annals of Internal Medicine* in 1996 (7).

The pneumococcal vaccine is recommended in all patients after age 65, and in those older than 18 with chronic organ disease, HIV disease, sickle cell disease, and asplenia, those older than 55 who are institutionalized, and those with spinal cord injury (7, 8). This vaccine should be considered in any patient with a neuromuscular disease. The influenza vaccine is recommended yearly for those older than 65 and for any adult with chronic disease, living in a chronic care facility or who is employed (6). All adults should receive a tetanus-diphtheria vaccine every 10 years (6). A hepatitis B vaccine should be given to health care workers, intravenous drug users, and patients with multiple sexual partners (6). The hepatitis A vaccine should be offered to all persons traveling to an endemic country, in addition to homosexual men, intravenous drug users, those with chronic liver disease, and those with an occupational risk (7).

A Rubella level should be checked in women of childbearing age and offered to all adults. The measles vaccine is given to all patients born after 1956, and a revaccination is necessary for those who received the vaccine between 1963 and 1967. A reliable history of varicella is adequate proof of immunity, but the vaccine should be offered to health care workers, household contacts of immunocompromised people, and those with high exposure (school personnel, day care workers, young adults in college or the military). It should not be given to pregnant women.

Lifestyle Issues

Many of these issues are not unique to those with disabilities. However, they are often overlooked in this patient population. It is important to counsel patients on the hazards of substance abuse, and the need to stop smoking and limit excess alcohol. The need for safe sex practices should be emphasized, and birth control should be discussed. Injury prevention, both vehicular and occupational, needs to be addressed. This is especially important for physically impaired persons, working with equipment that has not been adapted to them. The need for stress management and a good evaluation for depression is necessary in these patients, and especially in those over the age of 65. At each visit, an emphasis on monitoring for domestic violence and abuse is imperative in this population.

Secondary Disability Prevention

For those persons living with a disability or chronic condition, it is paramount to their continued independence to prevent the occurrence of a secondary disability. For this could well lead to a loss of work and, more important, to a loss of independence in activities of daily living. The primary health care provider may not be aware of these issues or may not realize the consequences.

It is important to preserve the strength of the patient. The slightest decrease may result in the

loss of ambulation or self-care. Simultaneously, the prevention of contractures and skeletal deformities is necessary. The maintenance of good skin integrity and the prevention of pressure sores is paramount in this population. It is also imperative to maintain adequate function of both the bowel and bladder. This should be individualized according to the patient's impairment and disability. The prevention of infection, especially of the bladder and lungs, is a necessity. If these organs are maintained, then the person will be able to preserve his or her functional level of independence. And this ultimately will prevent rehospitalization. Finally, the emotional and social adaptations to living with a disability must be recognized and provided for. Support and training are needed, not only for the patients, but also for the family and the caregivers.

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