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Aging with Physical Disability

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Introduction

Dramatic increases in life expectancy over the past century have resulted in population aging around the world. In the United States, life expectancy increased from forty-seven years in 1900 to about 78 years in 2009 (Administration on Aging, 2009). Until the 1970s, persons with disabilities faced lower life expectancies than their non-disabled peers. In the 1950s, the life expectancy post-spinal cord injury was only 3 years due to high rates of mortality related to urinary tract infections and other disability-related complications (Kemp & Mosqueda, 2005). Advances in medicine, rehabilitation, public health and technology have reduced this disparity in life expectancy for persons with disabilities and the life expectancy for persons with SCI is presently 85 percent of the general population. These gains in life expectancy have changed the demographics of disability; for the first time significant numbers are living long enough to reach old age.

The prevalence of aging with disability is unknown but best estimates indicate that about 27-39% of adults with disability had the onset prior to age 44, 25 to 32% had disability onset between ages 45 to 64 years, with the remainder of onset occurring in later life (Verbrugge & Yang, 2002). An estimated 12 million Americans with disabilities acquired in early or mid-life are aging with disability—and these numbers will continue to increase in future decades. This phenomenon is occurring worldwide although international numbers are not available. Impairment groups that have seen significant increases in long-term survival include cerebral palsy, spina bifida, muscular dystrophies, spinal cord injuries, polio, and rheumatoid arthritis. Population estimates for specific impairment groups in the United States are summarized in Table 1. Worldwide estimates are unavailable.

Table 1. Aging with Physical Disability: Common Diagnoses in the United States

Diagnostic Condition	U.S. Population Estimate
Polio	1,000,000
Cerebral Palsy	764,000
Spinal Cord Injury	250,000-400,000
Rheumatoid Arthritis	3,000,000
Multiple Sclerosis	400,000

Source: Putnam, 2007

Functional Status

Aging is a lifelong and developmental process; chronological age is a poor measure of most aspects of aging. It is multifactorial, reflecting the cumulative impact of decades of decisions and behaviors that affect function and health outcomes in later life. The effects of aging are often felt earlier among persons with disabilities; the long-term impact of impairment can impose additional stress on physiological systems. Efforts to maintain function and minimize disability have shown that small changes made earlier in life can have a profound impact on health and well-being in later life (Kemp & Mosqueda, 2005). For example, use of appropriate assistive technologies to minimize impairment related wear and tear can delay or avert changes in mobility. However, much remains unknown at present about many of the specific health risks associated with disability and how to prevent many of the secondary health problems associated with aging with disability.

After the age of 30, organ systems decline on average at a rate of 1 percent per year. In most older adults, normal age-related changes are fairly benign and do not affect the ability to perform activities of daily living. Some changes can be delayed or even reversed. For example, decreases in musculoskeletal strength can even be offset through strength training. However, with advancing years of age, rates of chronic health conditions rise and are closely associated with increasing functional limitations. A growing body of literature points to the environment (social, cultural and physical) as an important mediating factor in aging with disability (Putnam, 2002).

Health Status and Secondary Health Conditions (SHC)

A growing number of nations are recognizing the importance of maintaining the health and well-being of persons with disability. Self-reported health status is one of the most common measures used for assessing population health. But persons with disabilities, even those with similar conditions or impairments, vary considerably in their perceived health. Factors that influence perceived health status include the severity of disability, type of activity limitation, age of the person, age at onset and duration of disability (Krause & Broderick, 2005, Pentland, McColl, & Rosenthal, 1995). A recent study found that adult onset groups were significantly more likely than the early onset group to report fair/poor health (Lammom et al, 2008). One explanation for this difference is that persons with early disability onset and longer duration have had more time to adjust and adapt to a disability minority group identity (Thompson & Yakura, 2001). In contrast, individuals acquiring disability later in life may have a greater difficulty adjusting and may report their current health status in relation to their pre-disability health (Fitch & Robinson, 2003).

Disability has long-term health and functional consequences. The nexus of aging and lifelong disability is a new phenomenon and as persons with disabilities experience the benefits of increased longevity, they are also facing new challenges to their quality of life and well-being. Disability is not a static condition but rather a process of continuous adaptation to changes across the life course. When the process of aging is superimposed on disability, it can be difficult to separate out changes associated with aging from those associated with disability. Age-related health conditions (AHCs) refer to chronic conditions and diseases associated with aging that often occur more frequently, more severely and at an earlier age for persons aging with physical

disabilities (Campbell, Sheets & Strong, 1999; Rimmer, 2005). This phenomenon has been described as "accelerated aging" in the sense that health and functional declines associated with old age were occurring in midlife when people were unprepared for them (Campbell, Sheets & Strong, 1999).

Individuals aging with disability are also at risk for secondary health conditions (SHC). SHCs refer to any additional impairments, functional limitations or disabilities that occur as a result of having a primary disability (Wilber, Mitra, Walker, Allen, Meyers & Tupper, 2002). Common SHCs include pressure ulcers, spasticity, urinary tract infections, bowel problems, chronic pain, chronic fatigue, breathing problems, or depressive disorders.

Other SHCs such as those associated with the neuromuscular system can cause impairments in balance and increase the risk of falls. Similarly, loss of bone mineral density increases the risk of fractures. Cardiopulmonary changes decrease activity tolerance.

Among the most common SHCs associated with aging with disability are physical symptoms that include pain, fatigue and weakness. These symptoms threaten independence and quality of life if left untreated. Although new symptoms of pain, fatigue and weakness are common with aging among persons with disabilities, they are not "normal" aging and intervention is needed to address new symptoms to prevent additional disabling effects. For example, muscle and joint pain can be a warning sign of tissue damage. A thorough workup to identity the cause of the pain is essential to preserving function and preventing additional injury.

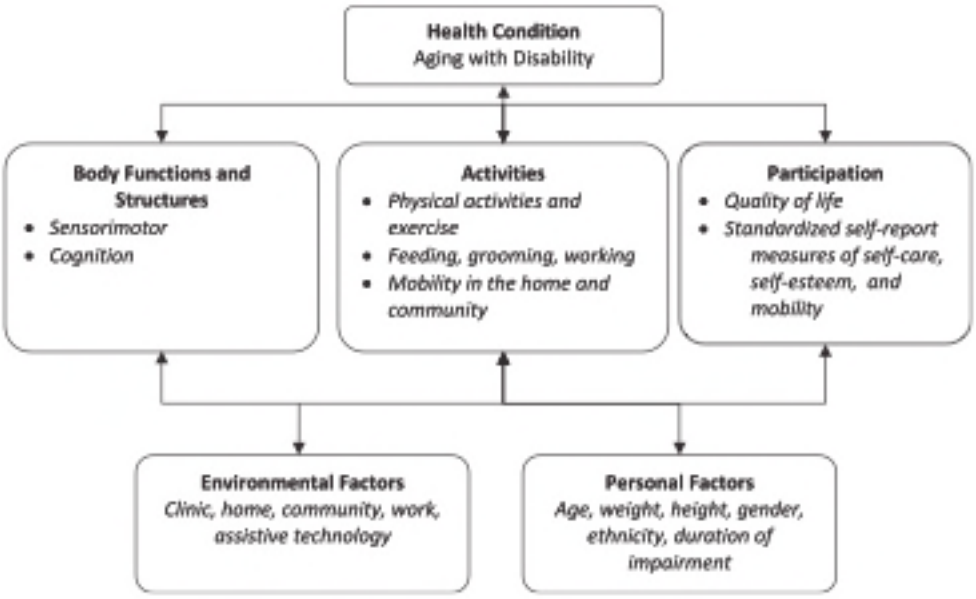
Fatigue occurs three times as frequently in persons with disabilities as in the general population (Thompson, 2005). It is characterized by lack of energy, inability to perform routine activities and feeling tired. Fatigue is extremely debilitating but it is often overlooked or not fully investigated because confounding factors that include poor diet, depression, lack of sleep, stress and other medical conditions, can make it difficult to address. The underlying cause of fatigue needs to be evaluated before it can be effectively treated and managed. Pacing activities and other lifestyle modifications that focus on conserving energy can help maintain quality of life.

Muscle weakness is also a common symptom among persons aging with disability. Subjective reports of feeling weaker are well documented, particularly among persons with cerebral palsy and spinal cord injury (Thompson and Yakura, 2001). Muscle weakness is associated with muscle and joint pain, deconditioning of muscle groups and sarcopenia. Upper extremity weakness can contribute to difficulty with transfers, propelling a wheelchair, or lifting objects. Lower extremity weakness may cause difficulty in rising from a chair, climbing steps, or can cause frequent falls or other mobility problems. Regular exercise can help maintain health and prevent injury by increasing overall energy reserves, endurance, strength, and cardiovascular function. However, the amount of physical activity must be balanced with concerns about reduced reserves and whether additional demands may be detrimental.

SHCs are problematic even though they are preventable and treatable. The ICF Model of Aging with Disability (see Figure 1) illustrates how health can impact on 3 outcomes: body functions, activities, and participation (Lange, Requejo, Flynn, Rizzo, Valero-Cuevas, Baker, Winstein (2010), SHCs have a direct impact on well-being and quality of life (QOL) by impairing

function, limiting activities and reducing participation for those aging with disability. SHCs also impose a considerable economic burden on healthcare systems by increasing rates of physician visits, hospitalizations, and other health-related expenditures (Hitzig, Tonack, Campbell, McGillivray, Boschen, Richards & Craven, 2008). What is clear is that aging disability populations need increased resources for prevention and treatment of SHCs. In addition, research is needed to understand the frequency, severity, and duration of SHCs and the impact of aging (Hitzig et al, 2008).

Figure 1. ICF Model of Aging with Disability (Lange, Requejo, Flynn, Rizzo, Valero-Cuevas, Baker, & Winstein, 2010)



Falls

Falls are a major risk for persons aging with a physical disability. A fall is an unexpected event, typically during the performance of daily activities (e.g. walking, transferring) in which the individual comes to rest on the ground or floor. Recent findings indicate that fall rates among persons aging with physical disability may be double that of their nondisabled older adult peers (Finlayson & Peterson, 2009). Fall risk factors are multiple and interacting. Mobility devices, such as using a cane, are associated with higher rates of falling among persons with disabilities. Walking aids have been associated with double the risk of falls compared to persons who use a wheelchair for mobility (Finlayson, Peterson & Cho, 2006). There remains a serious gap in research on falls and epidemiologic data needed to inform effective fall prevention and management programs for persons aging with disability.

Supportive environments

Changes in the health and functioning of persons aging with disability can be addressed by assessing needs for supportive environments and services (Brandt & Pope, 1997). Independence and quality of life can be maximized with access to appropriate assistive technology, home modifications and/or personal assistance. Often persons with disabilities adapt themselves to the

environment rather than adapting the environment to their needs. Providers need to screen for health and functional declines by asking questions that will reveal changes in functional status, new symptoms or additional needs for support.

As individuals grow older their strength, body size, and functional requirements will change. New needs will arise for mobility devices, home modifications, bathing and toileting equipment and other assistive devices. Assistive devices are often used when they are no longer safe or appropriate for complex reasons that include lack of knowledge, costs or fear of stigma. Recommended equipment may be more readily adopted when they are perceived as "tools for living"—and not a sign of increased disability or dependence.

Conclusion

A body of literature on aging with disability continues to develop. Recent research is deepening our understanding of changes in functional and health status. In future years, early interventions may help maximize function and minimize secondary health complications and debilitating symptoms such as pain, fatigue and weakness.

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