International Encyclopedia of Rehabilitation

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Age Related Disabilities – Aging and Quality of Life

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Introduction

With increasing age comes increased likelihood of disability. This is because as people live longer and do not encounter fatal diseases, their illnesses are chronic instead. The association between increasing age and increasing disability has led to a negative image of aging. Some gerontologists have introduced the term 'successful aging, emphasizing the point that not all aging is negative. This, however, has led to the possibility of stigmatizing older adults who have a disability. To avoid this problem, Kennedy and Minkler (1998) argue for a dialectical vision of aging wherein both able-bodied and disabled bodies are all part of aging. As Zola (1993) pointed out "the issue of disability for individuals … is not whether but when, not so much which one, but how many and in what combination". This paper discusses the disabilities that are likely to afflict us during old age, the fact that disability is not a characteristic of the individual per se but rather of the intersection between the individual and their environment, and the potential of therapeutic environments to maintain or increase quality of life for older adults.

Aging and Disability – What Does it Look Like?

It is important to note that one grows old gradually, one does not suddenly become old when they turn age 60 or 65 or 70. Physical health does decline with age; this does not necessarily mean that older adults are incapacitated, or, in the language of some, handicapped. Disability is usually defined in terms of restrictions in the ability to perform activities of daily living (ADL), or, the inability to function independently in terms of basic ADL or instrumental ADL (World Health Organization [WHO], 2003). Mobility disability is particularly important because the ability to ambulate is critical to so many activities that allow us to be independent. The International Classification of Functioning, Disability and Health (WHO, 2001) defines disability as, "the … result of complex relationships between an individual's health condition and personal factors, and of the external factors that represent the circumstances in which the individual

lives". This latter definition is important because it points to a relational perspective often forgotten when simply diagnosing physical ability. In gerontology, it is popular to discuss 'the disablement process', a dynamic interaction intimately tied to cultural norms and socioeconomic status encompassing attitudes, emotions, stigma, accessibility or lack thereof of various services, wheelchair accessible buildings, etc.

The WHO (2003; 2006) estimates that 10% of the world's population has some form of a disability, 20% of those aged 70+, and 50% of those aged 85+. That is, with increasing age, disability increases and, among those who are elderly (age 65 and over), the old elderly are more likely to experience disability than are young elderly. For this reason, the WHO argues that in terms of disability, old age can be viewed as starting at age 75. It is noteworthy that the oldest old are the most rapidly growing segment of the population and it is among the oldest old that severe disability is the highest (Ferucci, et al., 1996). While recent reports of declining rates of disability in some countries have lead to optimism, the trend does not characterize all nations. For example, a declining trend in severe disability is evident in the U.S., Italy and the Netherlands but it is stable in Australia and Canada and is increasing in Sweden and Japan (OECD 2009; Manton 2008). Furthermore, it is as yet unclear as to whether any trend toward decreasing rates will continue or spread. Increases in the prevalence of obesity threaten the trend where it is evident.

The most common causes of disability among older adults are: chronic diseases, injuries, mental impairment, malnutrition, HIV/AIDS and other communicable diseases. The major chronic conditions of an aging society include: cardiovascular diseases, hypertension, stroke, diabetes, cancer, chronic obstructive pulmonary disease, muscular-skeletal conditions including arthritis and osteoporosis, mental health conditions such as dementia and depression, and blindness and visual impairment. Injuries can be due to road traffic accidents, conflicts, falls, and land mines (McKenna et al. 2005). Certain chronic conditions are particularly related to disability including stroke, diabetes, cognitive impairment, arthritis and visual impairment. (Jagger et al. 2007a; Andrade 2009; McGuire et al. 2006). For adults with arthritis, the odds of disability rise with age, diminish with education and are higher for non-whites and non-married persons (Verbrugge 1991). Schoppera and colleagues (2000) and Melse et al. (2000) emphasize the importance of mental health problems, notably depression (and also isolate the importance of osteoarthritis, alcohol abuse, and lung disease) in the elderly. In addition, smoking is estimated to cause or aggravate several chronic conditions that amount to 18% of the total disability-adjusted life years (DALY) lost (WHO 2005). Throughout the world, it is found that the poor and uneducated males are most likely to smoke.

Rates of disability vary by country - less than 1% in Kenya and Bangladesh, 20% in New Zealand (Mont 2007), and 19% in Latin America and the Caribbean (Rose et al. 2008). However, the percentages must be interpreted with extreme caution. The generally poor health care, poor nutrition and unsafe living conditions lead to a questioning of the low disability rates in developing parts of the world. Different studies use different definitions of disability, different data collection strategies, and different research designs, as well as differing thresholds for defining disability. As Mont (2007) notes, some measures focus on body and function (sometimes referred to as impairment), some on activity limitation, and some on participation restriction. Different studies measure disability as: self-identification as disabled, diagnosable

conditions, activities of daily living, instrumental activities of daily living, and participation. Asking an individual whether they have a disability usually results in the lowest rates of disability. Questions asking about basic activities of daily living or major bodily functions result in better data (such as do you have difficulty walking? Or do you have difficulty holding a conversation with others?)

Mont (2007) notes that when more comparable data can be accessed, the gap between developing and developed countries shrinks somewhat, although not entirely. Furthermore, in high income regions of the world, generally 90% of the expected disability results from non-communicable diseases and most of the remainder to injuries, whereas in poorer regions, almost half of the expected disability results from communicable diseases and injuries (Murray and Lopez 1997). It would be helpful if, when reporting prevalence, authors provided both a disability prevalence rate and a severe disability rate.

Overall, women experience more disability in old age than do men. Jagger et al. (2007a) report this gender difference in the UK, with older women less likely to be disability free than older men. The same is true of the U.S. and Canada (Chappell and Dujela 2008). Similarly, Sagardui-Villamor and colleagues (2005) report the similar gender differences in Spain and der Wiel and colleagues (2001) in the Netherlands. Andrade (2009) notes that Mexican women live longer, but experience higher disability than do men. Exceptions to these findings are reported by Murray and Acharya (1997) for sub-Saharan Africa. Severe disability is associated with higher rates of mortality among both men and women. However, women generally survive longer and with greater disability than men. That is, while women are more likely to have poor health as measured in terms of disability they have longer life expectancy than do men. Reasons for this well-documented gender difference are unknown.

In addition to gender differences, socio-economic status, whether one lives in the developed world or the developing world, and ethnicity are among some of the factors related to the extent of disability experienced in old age. The relationship between disability and poverty cannot be over-emphasized. Poverty can lead to malnutrition, poor health services and sanitation, unsafe living and working conditions etc. that are associated with disability; disability can also trap people in a life of poverty (Mont 2007). For example, in England and Wales, Jagger and colleagues (2007b) found that differences in education contribute to the prevalence of disability; even older adults with less than nine years of education are more likely to experience disabilities, independent of diseases. Murray and Acharya (1997), when comparing regions around the world, find that established market economies are likely to have lower rates of disability (15% versus 8%). Kominski and colleagues (2002) report that in the United States, African Americans suffer the highest rates of disability, followed by American Indians, Whites, Latinos, and Asian Pacific Islanders. Similarly, studying only those with arthritis, Verbrugge (1991) in the U. S. reports that the odds of disability rise with lower education and are higher for those who are non-white and are non-married.

A further methodological note, though, is required when examining this literature because disability can be measured differently from study to study. A popular measure is the DALY (Disability–Adjusted Life Year), incorporating potential years lost due to premature death plus years of healthy life lost because of being in a state of poor health or disability (Murray 1994).

Despite many criticisms (Anand and Hanson 1997; Üstün et al. 1999), DALY does not take into account pain or suffering, reduction in well-being, or an individual's ability to cope; its standard of life expectancy is that found in developed and not developing countries; middle aged individuals are valued over infants and older adults; the assumption of universality of the disability weights are used. Nevertheless, it is an improvement over previous measures that do not take disability into account. The World Health Organization's disability assessment schedules (WHO-DAS) include 12 activity and participation based questions. Some are internationally comparable, such as standing for long periods, but others are more questionable, such as conducting household responsibilities. Those interested in any particular area of the world or any particular study must look carefully at the definitions and measures of disability, the methodology of data collection and study design, as well as the purpose of the study (monitoring level of functioning in a population, designing service provision, or assessing equality of opportunity) before comparing figures.

Interestingly, the rates of life satisfaction (happiness, well-being) tend to be high among older adults despite their decline in physical health and living with a disability. For example, in the U.S., 94.4% of older adults report being satisfied or very satisfied with their lives (Strine et al. 2008), in China 77.8% report being quite or very happy (Appleton and Song 2008), in Canada over 90% say they are satisfied or very satisfied with life (Statistics Canada, 2008), and in both Italy and Germany older adults score 7.5 out of 10 on a life satisfaction scale (Gagliardi et al. 2008). Ferring and colleagues (2004) similarly report 'content' older populations in the Netherlands, Luxemburg, Italy, Austria, United Kingdom, and Sweden.

Part of the discrepancy between declining health, increasing disability and maintenance of high levels of overall well-being is probably attributable to the fact that not all disability leads to dependence. If the consequences of disability in terms of limiting individual autonomy and creating dependence can be reduced or eliminated altogether, its negative effects on quality of life can minimized. This leads to a discussion of the environment and improvements in lifestyle. Improvements in lifestyle and health behaviours include, for example, better nutrition, not or quitting smoking, less obesity, and greater physical activity (Fries 2002; Hubert et al. 2002) which can help prevent stroke, CHD, and diabetes, all of which are related to disability in later life. For example, benefits accrue from exercise even when begun later in life; it serves to postpone disability. Berk et al. (2006), Guralnik et al. (2003) and Spirduso and Cronin (2001) are among the many researchers who have demonstrated the benefits of exercise for physical health. A meta-analysis by Conn and colleagues (2002) confirms the benefits of exercise.

The environment also plays a critical role in the effects of disability on the lives of older adults. The environment is modifiable, such as air, soil and water pollution with chemicals or biological agents, ultraviolet and ionizing radiation, the built environment, noise, electromagnetic fields, occupational risks, agricultural methods, irrigation schemes, anthropogenic climate changes, ecosystem degradation, as well as individual behaviours related to the environment such as hand washing and food contamination with unsafe water or dirty hands (WHO 2009). An environment which embraces accessible design and fosters independent living can make a difference in terms of a good quality of life for those with disabilities.

Quality of Life and Therapeutic Environments

Whether individuals with age-related disabilities reside in community or institutional dwellings, the physical environment serves as a valuable resource by which their remaining cognitive and physical abilities can be supported (Iwarsson 2005; Oswald et al. 2007). Verbrugge and Jette's (1994) disablement process model and Lawton and Nahemow's (1973) competence-environmental press model both examine the relationship between the physical environment and disability. Verbrugge and Jette (1994) distinguish between intrinsic ability (i.e., an individual's ability to perform an activity regardless of context) and actual ability (i.e., an individual's ability to perform an activity when supported by the physical or social environment). According to the model, the physical environment has the potential to help an individual overcome his or her intrinsic disability through either the removal of environmental barriers or the provision of environmental modifications.

While the disablement process model provides a framework for understanding the role of the environment in the disablement process, Lawton and Nahemow's (1973) competence-environmental press model offers insight into the mechanism by which the physical environment and disability outcomes are linked (Wahl et al. 2009). Environmental press refers to the demand that the environment makes on an individual, while competence represents the ability of an individual to respond adaptively to such demands. An individual's functional performance is the result of interactions between competence and environmental demand, a concept more commonly referred to as person-environment fit. Central to the model is the environmental docility hypothesis, which suggests that the effect of environmental press on an individual's behaviour and well-being becomes greater as personal competence diminishes. When competence is inadequate to respond to the demands of the environment, excess disability may result. By modifying the environment to more appropriately fit an individual's ability, adaptive behaviour is promoted. An individual's competency may therefore be enhanced through the provision of environmental modifications. For individuals with lower competence, even minor changes to the environment can potentially result in a positive outcome (Iwarsson 2005).

Many older adults express the desire to age-in-place, that is, to remain in their own home for as long as possible (Gitlin 2003). However, for individuals with age-related disabilities successful aging-in-place may be compromised by environmental hazards or barriers, common in the homes of older adults. For example, Gill et al. (1999) report two or more hazards in 59% of bathrooms and in 23%-42% of other rooms. The European ENABLE-AGE project (Enabling Autonomy, Participation and Well-Being in Old Age: The Home Environment as a Determinant for Healthy Ageing) finds the mean number of environmental barriers present to range from 37 in the UK to 66 in Germany (Nygren et al. 2007). Iwarsson (2005) reports similar findings in Sweden. While common barriers include dim lighting, shadows or glare, tripping hazards (cords, loose throw rugs/mats, curled carpet edges), the absence of a kitchen work surface at a height suitable for sitting, bathroom sinks designed to be used only when standing, and hardware or controls requiring suitable wrist flexibility to operate, it is the absence of grab bars at the shower/bathtub and/or toilet that can create the most problems with accessibility.

Several studies have documented a link between home environmental modifications and functional ability-related outcomes (Wahl et al. 2009). For example, older European adults living in accessible homes, who perceive their home as meaningful and useful (i.e., support the

performance of activities at home) and who view their home situation as contingent upon their own behaviour (as opposed to external influences), are more likely to be independent in their daily activities and have better well-being (Oswald et al. 2007). Gitlin, Miller and Boyce (1999) report marked improvement in bathing ability and ADL performance following minor bathroom modifications. Brunnstrom and colleagues (2004) found that increased kitchen lighting improves the performance of several daily kitchen activities, while additional improvements in living room lighting increase quality of life and well-being. Mann and colleagues (1999) reported that the provision of assistive devices and/or environmental modifications significantly decreases functional decline.

The home environment can also influence the lives of caregivers. For example, caregivers of individuals with dementia report that single-story dwellings, open layouts with straight sight lines from one room to another, shower stalls large enough to accommodate a shower chair, and sufficient room around the toilet to facilitate transfers make caregiving tasks easy (Olsen et al. 1999). Gitlin and colleagues (2001) also found that, as a result of modifying their homes to address the challenges associated with caring for a person with dementia at home, family caregivers report reduced upset and enhanced self-efficacy in managing behaviours and functional dependency.

Generally, interventions that target an aspect of the home environment related to a specific functional ability have greater impact than more general interventions. Similarly, the more intense and skilled the home modification intervention is (e.g., those that involve more than a 1-day consultation) the greater the improvement is observed (Wahl et al. 2009).

Several methodological challenges exist in assessing the effects of home environmental modifications. Of central concern is the lack of common, psychometrically sound home assessment tools. This leads to a tendency to develop a home assessment measure solely for a particular study which, in addition to issues of reliability and validity, can make comparisons across studies difficult (Gitlin 2003; Wahl et al. 2009). Two promising assessment instruments include the Housing Enabler (Iwarsson et al. 2005), which examines dimensions of the physical environment relative to an individual's functional capacity (and thereby provides an indication of person-environment fit) and the Home Environment Assessment Protocol (Gitlin et al. 2002), designed to assess physical features of the home environment that support or hinder the functioning of individuals with dementia.

Many studies utilize a cross-sectional design, likely due to the time intensive nature and increased cost associated with repeated, one-on-one contact with participants. However, this restricts causal interpretation and inhibits a clear understanding of how the relationship between physical functioning and environmental modifications changes over time (Gitlin 2003). In addition, Wahl and colleagues (2009) argue that studies need to examine the impact of both the objective and perceived home environment, as focusing only on the objective overlooks the importance of experiential dimensions such as satisfaction and usability (Nygren et al. 2007).

When functional disability becomes too great for an individual to safely remain in his/her own home, a transition to institutional care may be warranted. Given the increasing number of individuals with dementia residing in such settings, much of the work examining the relationship

between the institutional environment and age-related disability has focused on dementia (Calkins and Weisman 1999). Research supports the value of a home-like atmosphere which residents are familiar with. Familiarity is enhanced by smaller-scale spaces and a variety of home-like furnishings (e.g., chairs with different patterns and textures, coffee tables, lamps, bookcases), flooring finishes (e.g., carpeting, hardwood), and window treatments, and unhampered by characteristics such as large multi-purpose living/dining areas, uniform vinyl-covered furniture and linoleum flooring. A non-institutional character is associated with improved resident intellectual and emotional well-being, enhanced social interaction, and reduced agitation and aggression (Sloane et al. 1998; Zeisel et al. 2003).

Visually and physically accessible toilets, short hallways, handrails along both sides of the hallway, a cluster or household floor plan, and a walking path with inviting destination spaces support residents' daily functioning by compensating for their reduced cognitive and physical abilities (Cohen and Weisman 1991). In contrast, long hallways with few places to sit, considerable distance between common spaces and resident rooms, and the limited use of handrails are environmental barriers that can increase resident dependence upon staff. In a recent British study (Parker et al. 2004), residents in care homes that offered greater functional support for cognitive incapacities exhibited increased positive affect while residents in homes that compensated for physical and sensory challenges displayed the greatest control over their immediate environment.

The visibility of exits is of central importance to the safety and security of residents with dementia. Camouflaged exits (e.g., murals, cloth panels) or blinds at exit door windows can reduce elopement attempts (Dickinson and McLain-Kark 1998; Kincaid and Peacock 2003). Residents in facilities with camouflaged exits and silent electronic locks are also found to be less depressed (Zeisel et al. 2003).

Many individuals with dementia experience impaired spatial cognition which can make navigation difficult. Physical landmarks, decorating schemes (e.g., hallways with a garden vs. ocean theme), easy-to-read and well-placed directional signs, personalized entryways to resident rooms, short hallways, furnishings unique to specific areas, and cluster or household floor plans in which bedrooms and common areas are located in close proximity to one another are all features that facilitate resident orientation (Cohen and Weisman 1991; Zeisel et al. 2003). Such features are associated with positive resident emotion (Parker et al. 2004). In contrast, large-scale units, large multipurpose common areas, limited visual access to common areas from resident bedrooms, and unfamiliar institutional equipment (e.g., lifts, laundry carts) can hamper residents' efforts at orientation (Cohen and Weisman 1991).

Methodological issues associated with the examination of therapeutic institutional environments centre upon the use of small sample sizes (typically less than 30 residents), the absence of comparison groups or the use of non-equivalent comparison groups, all of which influence the validity and generalizability of findings (Day et al. 2000). Also, the nursing home setting is complex; consequently, the physical environment cannot be examined in isolation from the social and organizational context. The challenge is how to "account and control" for such factors when examining the impact of design features (Calkins 2001). Nursing homes tend to include multiple design interventions (e.g., home-like finishes/furnishings , smaller unit size) which

makes it difficult to identify which features are central to improving quality of life or how such features can support or detract from one another (Day et al. 2000). Given the cognitive impairment of many nursing homes residents, experiential information is rarely collected; however, examining the perceptions of residents in the early to middle stages of dementia may help improve the quality of research (Day and Calkins 2002).

Therapeutic environments, be they community or institutional in nature, should promote wellness and should support individuals in coping with the stresses that accompany age-related disability (Schwarz and Brent 1999). As demonstrated here, focusing on the physical environment as an intervention or treatment modality offers a means by which to help alleviate such stress and improve older adults' quality of life. Working together, health care professionals, researchers, designers and stakeholders can optimize the therapeutic nature of community and institutional dwellings.

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