



Aging with a Disability

RESEARCH TO CLINIC

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CLINICAL PERSPECTIVE - CEU ARTICLE

INTRODUCTION

We use research information to assist in informing our clinical practices. We must extrapolate facts and information from studies that are relevant to evaluation for, and intervention with, seating and wheeled mobility. Information can be a double-edged sword. A marquee in Colorado Springs reads, "We are drowning in information but starving for wisdom." Upon further investigation, the quote was found to be by Edward Osborn Wilson and is completed with, "The world henceforth will be run by synthesizers, people able to put together the right information at the right time, think critically about it, and make important choices wisely" ([Brainyquote.com](https://www.brainyquote.com/quotes/edward-osborn-wilson-1234567)). This is a two-pronged issue — information and wisdom, and the balance of the two. The wisdom comes from our cumulative experiences with our clients that we can integrate into our practices. The information comes from research and other literature. One cannot be employed without the other. The stories of our clients, combined with our professional responsibility to stay current in our fields, allow us to guide our clients toward choices that are wise for them. Then, like the title of Dr. Seuss's book, "Oh, The Places You'll Go!" If you work in the field of complex rehab technology (CRT), you need to be aware of the affects that aging can have on those with disabilities. This is true whether you are a professional who primarily works with adults or children. Hopefully, information that is learned from those who are aging can help inform therapy practices in children.

The information around aging with a disability applies to both those who acquired a disability or who were born with disabilities. Signs of aging can show up quite early relative to those who do not have a disability. For example, if someone acquired a spinal cord injury at age 16 years, they may be only 36 years old 20 years post injury but could have difficulties more common in people who are chronologically older. For persons who have had a disability since birth, their age equals the time "post-

injury." It amounts to the same thing: living a certain amount of time with a physical disability can change the way one functions and is able to participate (Taylor, 2017).

REHABILITATION AND ITS RELATIONSHIP TO DISABILITY OVER TIME

Life expectancy increased from about 47 to 77 years of age between 1900 and 2000. As recently as 1945, the life expectancy of an able-bodied person was 55 years, while life expectancy was only two years following a spinal cord injury. Nowadays, the life expectancy of most individuals with acquired disabilities is 85% of those without physical disability. It is estimated that about 12 million people in the United States are disabled (Kemp and Mosqueda, 2004).

Until about 1945 (WWII), no organized rehabilitation existed. During the 1940's, rehabilitation was "born" as a profession



to re-integrate those who had sustained injuries in the war back into society. During that era, the prevalent attitude was that one could overcome anything if one tried hard enough. Society was not set up for those with disabilities, so people were encouraged to “fit in” and be productive in society (Kemp and Mosqueda, 2004).

The 1960s and early 1970s saw the rise of the disability rights movement, which paralleled other human rights movements of the same era. These movements drove the idea that access to society literally become accessible. The passage of the Americans with Disabilities Act (ADA) in 1991 was a first step in this process. At the same time, due to improvements in emergency care, more people were surviving serious accidents and incidents. Into the 1970s and early 1980s, large numbers of people with disabilities were living into middle and older ages, and it became clear that signs of early aging were evident and could not be ignored. Many clients did not anticipate these changes, and many clients were, and continue to be, caught off guard by the changes that they experienced. The first large group to experience these functional changes were those who had been living with the effects of polio. These clients were taught that hard work would overcome all and that one must rely on oneself. Their lives had revolved around exerting huge efforts on a daily basis, as if one had to run a marathon every day. The attitude was “Use or Lose it” (Taylor, 2017).

Beginning in the 1980s-'90s, studies of the physical, psychological and sociological aspects of aging with a disability revealed some troubling trends. From the late 1990s through the present, enough relevant information has become available to incorporate into everyday clinical practice.

What is the scope of the issues? Begin with the perceptions of those who are living with a disability. A recent study by Molton and Yorkston (2017) gathered 49

adults between the ages of 45 and 80. Diagnoses included muscular dystrophy, multiple sclerosis, post-polio syndrome and spinal cord injury. They conducted a focus group with the theme of what successful aging looked like to them. The researchers came up with four areas:

1. Resilience and adaptability: The interviewees defined this as having a positive outlook and being able to adapt to changes.
2. Autonomy and choice: Maintaining control over life decisions such as what kinds of adaptive equipment to use.
3. Social connectedness: Strong relationships and being able to share experiences with peers.
4. Physical health and access to health care: Being able to maintain physical wellness to continue to participate in desired activities. Not only having access but also having health care professionals who understand their disability.

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Similar findings were revealed in a longitudinal study of individuals with spinal cord injuries that was carried out by James Krause. (Krause, et al., 2015).

THE AGING PROCESS

Theory in the field of aging delineates several different types of aging (Rowe and Kahn, 1998):

- **Successful:** These are people who have what we would call "good genes." Little change in function is noted until the early to mid-70s, with no chronic disease to limit function.
- **Usual:** This type is defined as positive or neutral genes that are revealed in a neutral or slightly negative environment. Although there may be some disease, this does not impair the individual's ability to function.
- **Pathologic:** These people are at serious risk of major functional limitations with severely limited independence.

It is not well understood how each person's genetics/lifestyle choices/experiences and the presence of a disability intersect (Rowe and Kahn, 1998). It was once thought that after rehab, the client would go out into the working environment with few changes: it is now known that functioning over time is quite a dynamic process.

A MEANS TO UNDERSTAND

The International Classification of Functioning (WHO, 2002) provides an internationally accepted common language and standard for describing function and disability (see Figure 1). Of course, this is how we conduct a seating and mobility evaluation. We examine impairments to body structures and functions and how these affect the client's ability to complete activities that allow them to participate. We ask and observe about environmental issues as well as factors that are unique to that client. The end result for the clinical team is to collaborate with the client on equipment and strategies that ultimately allow them to participate. First, common impairments that lead to secondary conditions will be overviewed.

SECONDARY CONDITIONS THAT EFFECT SEATING AND MOBILITY CHOICES

Secondary conditions form the basis of what needs to be understood and screened at a seating and mobility appointment. It is imperative that wheelchair seating and mobility professionals understand an individual client's diagnoses and impairments and the effects that aging can have on activity and participation. Many of the studies that will

be presented, and similar studies, are directly related to factors that should be screened during a seating and mobility evaluation. Much of the studies are centered on people with spinal cord injury, with a more recent increase in studies on people with cerebral palsy.

FIGURE 1 The International Classification of Functioning

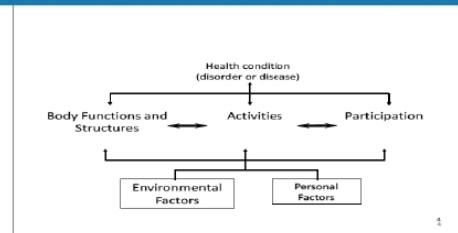


Figure 1: Interactions between the components of ICF (WHO 2001:18)

Sometimes clients just need new equipment and sometimes they are having an issue that effects their positioning and/or mobility with the current equipment. Clients often seek seating professionals for four areas of concern:

- Pain
- Fatigue
- New weakness
- New or recurring pressure injuries

Often, these symptoms have reached a point where the client can no longer ignore them. It has been noted by clients to seating professionals that pain, fatigue and weakness can be insidious; changing function here and there over time until the client has cut their life down to the "necessities" (Taylor, 2017), often giving up social aspects of life in order to maintain activities of daily living and other functional skills. Social aspects of one's life are hardly disposable. Many clients have related to this therapist that they didn't even realize how much they had given up until someone questioned them about it. Remember that social connectedness has been identified in many studies as one of the most important quality of life contributors.

PAIN

Musculoskeletal changes are the most obvious external signs of aging and are particularly affected by aging with a disability. A University of Washington study looked at 1,877 individuals with longstanding disabilities including Spinal cord injury, neuromuscular disease, post-polio syndrome and multiple sclerosis for prevalence and impact of pain. The researchers found that of several secondary conditions including pain, spasticity, fatigue, weakness and imbalance, the most common was pain - 25% to 33% of individuals rated their pain as severe. These symptoms can have a profound effect on quality of life and the ability to participate (Molton, et al., 2014). The researchers found that the degree to which these secondary conditions

interfere with activities varies widely and is based on the person's life context and environmental demands (Molton, et al., 2014).

As one can appreciate, the incidence of pain in those aging with cerebral palsy may be significant after years of functioning with joints that are mal-aligned or not well formed and/or in postures and using movements that lead to these orthopedic issues. The odds are higher in those who display more physical impairments (Whitney, et al., 2018). Soft tissue limitations leading to joint deformity over time can also increase pain and discomfort.

In older studies, Andersson and Mattson found that 79% of individuals with varied types of cerebral palsy had pain that was primarily in the hips, back and shoulders (Anderson, et al., 2001). Vogtle states that 67% of clients with cerebral palsy had one or more pain sites and identified back, hip and lower extremities as the biggest pain sources (Vogtle, 2009). Haak, et al. state that while there is not a huge amount of objective information on adults aging with cerebral palsy, anecdotal reports do indicate that many clients feel the effects of aging in their 20s, with decreasing function, increased spasticity and, if walking, decreased balance (Haak, et al., 2009).

In the study by Whitney, et al. (2018), the researchers introduce that over the past few decades, the "global disease burden" has shifted from premature death to many years lived with a disability, and from the prevalence of communicable diseases to non-communicable diseases. For this study, they included two broad areas: musculoskeletal morbidity (osteopenia, osteoporosis, osteoarthritis and rheumatoid arthritis) and cardiometabolic morbidity (stroke, hypertension and cardiovascular problems that can include peripheral artery disease and heart failure). They looked at prevalence of non-communicable diseases in a sample of 452 people with cerebral palsy and 448 people without the diagnosis, ages 18 to 30 years. The researchers found higher rates of these musculoskeletal and cardiometabolic issues in people with disabilities: 51% of participants had non-communicable diseases who scored at levels I-III on the Gross Motor Function Classification System, and 49% scored at levels IV and V. These musculoskeletal and cardiovascular conditions have the ability to greatly impact physical function. Whitney et al. also stated that by age 40 to 60 years, 60% of adults with cerebral palsy have multiple secondary conditions — this is 1.5 to 2.9 times higher than the general population.

The American Academy of CP and Developmental Medicine (www.AACPDM.org) has a Lifespan Committee on Adult Care and Aging. There has been a pointed effort on their part to identify issues in those aging with cerebral palsy as well as directing research efforts and topics to better understand changes that can occur over the lifespan. As stated previously, this knowledge needs to inform practices with children as necessary.

In spinal cord injury, there is an increase in upper extremity pain, decreased strength due to atrophy, and an increased risk for fractures (Hitzig, et al., 2010). The most frequently reported pain in this population occurs at the shoulder and wrist. The longer someone has been injured, the more common this becomes as increased physical demands and overuse of certain muscle groups intersect. This varies according to the individual: some people naturally have better joint integrity than others. Incidence of upper extremity pain in people with spinal cord injuries is between 30 and 70 percent (Sie, 1992, 2001; Pentland, 1994; Klingbeil, 2004).

In 1992, Sie looked at 239 people with spinal cord injuries who were an average of 12 years post injury: 55% of those with tetraplegia had upper extremity pain and

65% had shoulder pain: 64% of those with paraplegia had upper extremity pain, mostly shoulder and carpal tunnel pain (Sie, 1992). The Pentland study in 1994 demonstrated similar results. She found that 58% to 60% of males with paraplegia had shoulder pain that was related to time since injury, rather than age (Pentland, 1994). It should be noted that the same types of overuse syndromes of the upper extremities have been identified in clients with spina bifida (Klingbeil, et al., 2004).

One has to keep in mind that an increase in pain and contractures, especially in the shoulder, can lead to a dramatic decrease in function. Even a small decrease in range of motion can impact activities of daily living, such as pulling a shirt over one's head or propelling a wheelchair (Taylor, 2017).

Traumatic brain injury (TBI) survivors also have an increased prevalence of arthritis, as studied by Colantonio, et al. The authors speculated that the mechanism of injury, which included motor vehicle crashes, can lead to multiple injuries as well as prevalence of heterotopic ossification, both of which can lead to arthritic changes. Of 286 clients with moderate to severe traumatic brain injury, 30% identified arthritis as a major problem, as compared to 15% of the general United States population (Colantonio, et al., 2004).

FATIGUE

As interfering as pain can be, fatigue can also greatly impact one's ability to perform activities that allow participation. Fatigue in the general population is reported at 15% to 20%. Fatigue that interferes with the performance of activities of daily living is three times higher in populations with disabilities versus those who have no disabilities. There are several types of fatigue: central, peripheral and mental.



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- Central: characterized by exhaustion and a lack of energy.
- Peripheral: characterized by actual muscle weakness.
- Mental: an inability to focus on a task or stay alert.

Fatigue is insidious: clients report giving up a little here and a little there until their activities consist of the basics necessary to function day to day. As previously stated, clients report they give up "extras," like social activities to have the energy needed to, for example, transfer and dress.

Cook, et al. looked at 1,836 people in Washington State using the Patient Reported Outcome Measurement Information System. They found that not only did individuals with a disability have a greater risk for fatigue, but this risk increased with age (Cook, et al., 2011).

Another University of Washington study looked at 1,877 individuals with longstanding disabilities including Spinal cord injuries, neuromuscular disease, post-polio syndrome and multiple sclerosis for prevalence and impact of pain. (Molton, et al., 2014). Rates of pain and pain interference were compared to sample of adults without disabilities. Those with disabilities did not experience an age-related decrease in pain and pain impact that those without disabilities experienced after retirement age. Individuals with disabilities reported elevated pain and pain impacts that were significantly higher. They concluded that pain interference with function does not seem to depend on severity for those with the studied disabilities. The researchers discussed that basic tasks, such as moving and toileting continue throughout retirement, whereas those without disabilities were able to decrease activities that caused them pain issues. (Molton, et al., 2014). This can point the clinical team to ask questions regarding not only rating pain but also describing its effects on function and participation.

In a three-year study by Oude Lansink, et al. (2019), researchers found that 41% of adults with bilateral cerebral palsy rated themselves as severely fatigued. The overriding conclusion was that once adults with the disease reported fatigue, it was unlikely to change over time. The researchers state that health care providers need to understand the factors associated with changes in fatigue in order to provide surveillance, prevention and management beginning in younger life

FUNCTIONAL IMPAIRMENT SYNDROME

In 2001, Thompson and Yakura suggested a "functional impairment syndrome" after studying a group of clients that

had developed a constellation of symptoms including pain, fatigue and weakness. The Rehabilitation Research and Training Center at Rancho Los Amigos studied over 600 people with varied diagnoses who complained of these symptoms. They concluded that these symptoms occurred as a syndrome and usually predicted and led to major changes in function (Thompson and Yakura, 2001).

SKIN INTEGRITY/ PRESSURE INJURIES

Another area impacted by aging is skin integrity. This area has been studied in people who have spinal cord injuries, but not as much in those with other diagnoses. Clinically, clients often are surprised that they have developed impaired skin integrity after having no pressure problems for many years. As one with a spinal cord injury ages, sweating and fat decrease and the capillary walls grow thinner and are more prone to rupture. This can lead to decreased sitting tolerance and increased need for pressure relief (or development of the habit of shifting weight), as well as the need for protective equipment (Shea, et al., 2013). One can surmise that these findings also affect others with insensate skin, such as those with spina bifida.

Chen, et al., looked at 3,361 people from the spinal cord injury database. The sample included about the same number of those with tetraplegia and with paraplegia. This review showed that the incidence of pressure injuries was steady for about the first 10 years post injury, with an increase in incidence noted at about 15 years post injury. By 20 years post injury, there was a 30% increase (Chen, et al., 2005).

EVALUATION: HOW CAN THIS INFORMATION AFFECT OUR INTERVENTIONS?

"The Universe is made up of stories, not atoms" (Muriel Rukeyser, 1913-1980). Indeed, client's stories help us to understand their experiences and who they are so that, at the end of the evaluation, we can respectfully make professional suggestions. We need to listen carefully.

The ICF model (International Classification of Functioning, Disability and Health) should be used to perform seating and mobility evaluations. Assessing impairments and impact on activities and participation is done with specific questions and observations. We often hear, "I just want the same thing I have now." While it is tempting to simply duplicate equipment, the purpose of a professional is to assess a situation and provide professional advice. As previously mentioned, some clients have not really thought about the day-to-day of how their function may have changed, or that there are interventions and/or equipment that could mitigate the effects of secondary conditions. In a study by Thompson, et al., 78% of 54 clients with a functional decline had new equipment prescribed after assessment, whereas only 10% of these same clients thought new equipment was needed prior to the assessment (Thompson and Yakura, 2001).

INTERVIEW

The process of evaluating a client aging with a disability is the same as in any other seating and mobility evaluation: interview, hands-on mat evaluation, observation, functional evaluation and use of trial equipment to meet the client's goals. The clinician must LOOK, LISTEN AND FEEL. Listening is paramount. No one knows the client's function like the client and/or caregiver does. The clinician should assist clients in anticipating and identifying changes due to aging with a disability based on common problems that have been identified by research and anecdotal experience of the clinician in working with others (Taylor, 2017). The clinical team needs to "read the room," including not only the client's face and body language but also caregivers, if applicable. The success of an intervention depends upon everyone understanding and accepting the results of the evaluation.

Several primary open-ended questions for the client aging with a disability include "Why are you here?" "Is this a routine visit or is there a special problem?" "Is there an ongoing problem that has reached a critical stage?" Many times, symptoms of secondary conditions have gotten so bad that the client comes into clinic hoping to address these issues. Medical history, including diagnoses and onset of the primary diagnosis, as well as secondary diagnoses is collected. Surgical history, including skin and musculoskeletal procedures, as well as neurological interventions such as a Baclofen pump is reviewed. History of and current pressure injuries are discussed. Another area to explore are falls. There is a higher incidence of falls from both clients who are still fully or partially ambulatory (although impaired) as well as falls during transfers. Molton and Matsuda (2016) suggest that questions about types of falls, when they occur and whether they are associated with injuries are important. This can inform if and when equipment and techniques are safe and functional.

EQUIPMENT HISTORY

Obviously, the clinician and supplier need to determine the age of the equipment. Often, the equipment that the client is using is no longer available, so exact replacement is impossible. Even if it is to be an "exact" replacement, the equipment will feel different to the client (being new versus the wear and tear of older equipment) and this must be discussed. Also, it may be that the client's current funding is more restrictive than the funding previously used. Observe the current equipment and how it is used. For example; does he require back canes at a certain height to "hook" their arms around for balance? Observe the wear patterns of parts, as that can provide information about how the client sits and functions on their chairs and seating. For example, deep wear marks on the fabric of one side of the back support may indicate clients is sitting asymmetrically. The supplier also focuses on measurements of the existing equipment.

LIFESTYLE (CONTEXT) AND ENVIRONMENTAL FACTORS

Just as with any other seating evaluation, strategies the client and caregiver use for activities of daily living are discussed with an emphasis on where and how the chair and seating are used. It is very easy to get in the way of function with equipment when the details of how the client functions are not understood. This includes any of the client's environments, including home and work. If the client/caregiver have their own van or car, it is necessary to trial any equipment with this vehicle.

FUNCTIONAL EVALUATION

The clinician should observe as many transfers as possible; independent, assisted or dependent, to view what methods and what parts of the wheelchair are used and, as mentioned previously, if they are safe.

In these areas, the clinician should probe for details to determine if skill performance has changed over time, such as change in abilities or in performing a task that was once routine. Remember, some of these changes are insidious and happen over a long period of time.

MAT EVALUATION

In addition to the way a mat evaluation is typically performed, it is necessary to elicit client feedback on how hands-on support from the clinician affects the posture and ability to balance from head/neck through the trunk and pelvis. One can learn a lot from just observing how someone sits and moves, with and without support. For example, people become so used to sitting and moving in a certain way that they may not realize that the compensatory movements to which they have grown accustomed can affect pain and level of fatigue. The level of support needed can increase as the client ages, so increasing the support may not have been brought up to the client previously. While introducing hands-on support during the mat evaluation, the clinician must elicit client feedback on how much support is too much and pay close attention to the amount of pressure required to achieve and maintain a posture. This is a good time to ensure that the postural goals of the client ("I just want to sit straight again ...") are realistic in terms of what can be tolerated and what support equipment



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can provide. Nonverbal cues from the client, such as a concerned facial expression, can tell the clinician that the level of support applied may be too aggressive.

TRIAL EQUIPMENT

Trial equipment is, of course, necessary in all evaluations. Even if replacement equipment is being recommended, styles and the features of the equipment change over the years. As indicated above, this must be included in the conversation. Any postural intervention must be tried with the client, specifically with the client performing functional skills such as transferring, propelling the wheelchair, accessing controls on a power wheelchair, or accessing vehicle controls. Often, clients don't realize how much effort they have been putting into balancing and functioning until adequate support is provided (Taylor, 2017).

Based on client feedback over the years, it can be a relief to the client to have someone who is aware of the issues around aging with a disability actually listen and understand that changes are very difficult. The clinical team should remember that change is difficult for anyone, particularly someone who totally relies

upon the functional environment of a wheelchair and seating. Many clients are also relieved to hear that these are common problems and that solutions are possible. One must encourage the client to trial equipment without judgment. How suggestions are made are just as important as the suggestions themselves. Some clients do not want to "disappoint" the clinical team by disagreeing with a suggestion that is made. The clinical team is there to provide the information and opportunity. Ensure the client that there are tools that can be used to help make final decisions, and that the final decision is theirs alone.

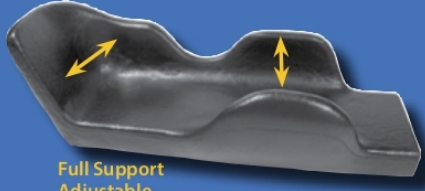
When we as seating professionals are seeing clients who are aging with a disability, we need to be prepared with knowledge of their condition and the anticipated progression and be prepared to trial equipment and ideas over a long period of time.

SUMMARY

In summary, there is now a great deal of available information on aging with a disability. This information should be incorporated into the clinical practice of the seating and mobility clinician. The clinician and the client need to consider the fact that there may be equipment and support surface changes required over time. With this type of


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evaluation, everyone is in it for the long haul. It is not that unusual for an evaluation and trial(s) or recommendations to happen over months and even years before the client decides it is time to make a change. The client, however, cannot make that kind of decision without information. A fully educated consumer is one who can make the best decisions for themselves. As health care professionals, we must understand and integrate past into present (Taylor, 2017).

Barry Corbet, a survivor of spinal cord injury (1968-2004) and editor of *New Mobility* magazine from 1991 to 2000, made a statement many years ago that can be applied beyond this diagnosis. An edited version is below:

"The SCI survivor must balance quality of life costs over the ability to stay independent. Bodies are abused far more by overuse than disuse. The use it or lose it maxim no longer washes ... instead of doing what's possible, do what is feasible."

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