Custom Sooner = More Meaningful and Lasting Outcomes

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Introduction.

Why, in the absence of a progressive neuromuscular or other disease, is the chronic deterioration of postural alignment and function so often regarded, even excused, as a normal result of long term sitting?

As medical and pharmacological care has evolved over the past decades, newborns are surviving events that a decade or two ago may have been deemed hopeless and fatal. Likewise, people are surviving and living long lives following traumatic events. The key word above is "events", not disease. Cerebral Palsy, Spina Bifida, Stroke, Spinal Cord Injury, Brain Injury, to name a few, are not diseases, but disabling events. The event itself does not result in a progressive condition, but the disability associated with the event can present with varying degrees of progression depending on numerous intrinsic and extrinsic factors. Seating is the art and science of managing the extrinsic factors in an effort to influence the intrinsic towards improved health and mobility.

We are the first generation of wheelchair seating professionals to witness the effects of these events on and associated with aging. Clearly there are differences between aging with and without a disability. For the person aging with a disability the changes can be slow and insidious. Charlifue et al., recognized multiple system degeneration over time in the Spinal Cord Injured population, and stated that true decline is more likely to be detected when the aging process begins to interfere with function. What can be done earlier to delay or even prevent this decline so it does not reach the threshold level of functional impairment? Are we too tolerant of or even missing early signs of age related changes that may respond to certain interventions if applied in a timely manner?

Aging With a Disability.

Certain outcomes related to historical wheelchair prescription are becoming increasingly well documented. Additionally, current literature provides an increasingly comprehensive picture of aging with a disability. Though much of the published work does not directly implicate or measure seating and mobility prescriptions' effect on the aging process, the list of issues at the forefront of discovery parallels limitations and concerns often expressed in seating and mobility assessments.

The trauma associated with long-term use of the upper extremities for manual wheelchair mobility is a prime example (Collinger et. al.). The advent of tools and related research that objectively measure these stresses, in conjunction with practice-based observations has made it especially clear, for one example, that promoting the use of manual mobility for people with cervical level SCI is a recipe for functional disaster. This discovery has led to a dramatic change in seating and mobility prescription for this population. This model of discovery moving rapidly into practice should be emulated by our industry as the body of knowledge surrounding issues of aging with a disability expands.

Fatigue.

Fatigue is well recognized as an outcome related to accelerated aging, and it is of particular concern as it has a number of negative effects on health problems, disability

problems, perceived temporal disadvantage and on quality of life. (McColl et al.). Interestingly, fatigue has been found to be greatest among people with spinal cord injury of shorter duration as compared to people with longer duration (McColl et. al.). Are people resigning themselves to a perception of lower energy levels as they age with a disability? Are their reports based relative to recent memories of pre-trauma lifestyle and energy levels? The finding clearly speaks to the need for maximizing efficiencies in function and mobility early on in an effort to decrease fatigue and improve quality of life.

Pain.

Pain is another common complaint of people with disabilities. Nosek et al. found that 94.5% of women with disabilities reported interference from pain, and 93.7% from fatigue over a one year period. Immobility and pain have also been linked. Jensen et. al., when studying chronic pain among persons with myotonic dystrophy and facioscapulohumeral dystrophy, found that prevalence of chronic pain is not associated with aging as strongly as it is related to immobility. Respondents using a wheelchair or cane reported the highest level of pain over those who did not use an assistive device for mobility. The connection between postural changes associated with age and pain has also been considered (Salisbury et al.). Postural deterioration over time has been well documented. Vogel et al. looked at complications associated for adults with pediatric-onset spinal cord injury and found that 40% had scoliosis, and 69% had pain. Once again these findings support aggressive and early intervention to preserve dynamic postural health for sustained mobility and pain management.

Skin Integrity.

Skin, as an organ, changes over time. These changes are magnified for people aging with severe disability. These progressive changes result in a reduction in the skin's tolerance of the extrinsic factors; pressure, shear, heat and moisture. Current practice and research have led to recognition of risk variables that are independently associated with pressure ulcers. Salzberg et.al. identified 7 independent factors out of a list of 15 from a previously published scale. These independent factors were established for risks related to paralysis: level of activity, level of mobility, complete spinal cord injury, urinary incontinence or moisture, autonomic dysreflexia, pulmonary disease, and renal disease. Notice that pressure is not identified as an independent risk factor, therefore it must be coupled with other factors to create risk for pressure ulcer development, e.g. pressure and time (as a measure of immobility), or pressure and moisture with shear. Recognize, however, that the mobility component presents as a clear and consistent factor.

Functional Capacity.

Any prolonged and persistent static posture could be deemed as pathological.
The absence of active mobility in and out of a variety of postures may predispose a person to chronic destructive postural tendencies that can lead to further impairment of mobility and functional capacity. Lung capacity and expiratory flow in standing is significantly superior to those measured in sitting and especially “slumped” posture (Lin F. et. al). Support of well balanced, dynamic and upright posture in sitting clearly influences functional capacity.

Seating and Mobility Prescription.

So we see that fatigue, pain, over-use syndromes, functional capacity, postural deterioration, and skin integrity are all correlated with mobility and activity. Pain, as cited above, appears to have an even greater correlation with immobility than with aging

itself. One's attention to age-related changes, and the discouraging statistics outlined above, should give all seating and mobility professionals pause. Are we doing all that can be done, and are we doing it in a timely fashion?

Immobility is the common thread coursing through all the literature reviewed for this paper. It is clear to this author that any seating and mobility intervention that does not improve a person's level of activity and mobility may not positively impact the frightening list of issues faced by our clients and customers as they age with their respective disabilities. How then do we improve the likelihood of restoring and preserving mobility?

Custom Sooner, Rather Than Later.

As posture deteriorates, especially into asymmetry, the spine flexes and rotates and the facet joints approximate and limit movement. The further one's posture deviates from midline and balanced, the greater the mechanical advantage of gravity for increased pull and destruction becomes. When flexibility through midline is lost so does one's ability to sit at midline. The greater the spinal asymmetry, the greater the negative impact on mobility. Any loss of mobility will likely result in complications previously outlined.

Historically, custom seating has been reserved as the last ditch option once all else has failed over a significant period of time. By the time people are identified for custom seating, they are likely to be presenting with significant loss of mobility secondary to postural deterioration with lack of flexibility towards correction. This loss of mobility is likely to result in increased fatigue, pain, skin breakdown, loss of functional capacity, and a myriad of other complications. Custom seating options, to some extent, have influenced this delay as traditional options were not a reasonable match for the active user. They were heavy and bulky, did not manage heat and moisture, could not be adjusted to accommodate growth and development, and had a mixed record, at best, for pressure management at bony prominences. The latest generation of custom seating overcomes the shortcomings related to earlier custom interventions. Custom seating can now be applied in a fashion that is skin safe, lightweight, breathable, thin in profile and growable.

Identifying candidates for early intervention with custom seating is critical. Funding sources require that all reasonable and less costly options be ruled out. Seating and mobility professionals should be very critical and have clear criteria for ruling out lesser options. They should resist the temptation to accept an outcome that is less than optimal, but perceived as "good enough". Sitting straight and upright at rest, and promotion and preservation of movement and flexibility through midline are the core building blocks for functional activity and mobility. It is important to recognize that a consistent and persistent asymmetrical postural tendency, even in the presence of flexibility and tolerance of correction, will likely require asymmetrical intervention to support a midline and balanced posture. If lesser options do not fully achieve the desired outcome, one can now consider custom options for correction and promotion of active and mobile postures, rather than simply face the future likelihood of custom options to merely accommodate and stabilize immobile postures. The earlier the intervention, the greater the likelihood of meaningful and lasting functional outcomes will be. Preservation of activity and mobility can be expected to have a positive impact on fatigue, pain, functional capacity, skin outcomes, and likely many more meaningful benefits.

Conclusion.
Seating and mobility professionals will better serve their clients by raising the bar for outcome measures associated with simple off the shelf modular seating. In the absence of a progressive neuromotor or other condition, they must resist the temptation to see postural and functional deterioration as a normal outcome of aging with a disability. Every incremental loss of mobility will have an impact on the factors listed. Your customers are not likely to mention changes or pursue help until a decrease in functional mobility impacts their quality of life, and by then it may be too late to intervene in a fully restorative fashion. It behooves us all to recognize early signs of deterioration and intervene quickly. Rule out simple interventions and be at the ready with custom should the situation warrant.

References:

1. Charlifue SW; Weitzenkamp DA; Whiteneck GG, Longitudinal Outcomes in Spinal Cord Injury: Aging, Secondary Conditions, and Well-Being. Archives of Physical Medicine and Rehabilitiation, 1999 Vol 80, 1429 – 1434.
2. McColl MM; Arnold R; Charlifue S; Glass C; Savic G; Frankel H, Aging, Spinal Cord Injury, and Quality of Life: Structural Relationships. . Archives of Physical Medicine and Rehabilitiation, 2003 Vol 84, 1137 - 1134.
3. Nosek MA; Hughes RB; Peterson NJ; Taylor HB; Robinson-Whelan S; Byrne M; Morgan R, Secondary Conditions in a Community-Based Sample of Women With Physical Disabilities Over a 1-Year Period. Archives of Physical Medicine and Rehabilitiation, 2006 Vol 87, 320-327.
4. Jensen MP; Hoffman AJ; Stoelb BL; Abresch RT; Carter GT; McDonald CM; Chronic Pain in Persons With Myotonic Dystrophy and Facioscapulohumeral Dystrophy. Archives of Physical Medicine and Rehabilitiation, 2008 Vol 89, 320-328.
5. Lin F; Parthasarathy S; Taylor S; Pucci D; Hendrix RW; Mohsen M; Effect of Different Sitting Postures on Lung Capacity, Expiratory Flow, and Lumbar Lordosis. Archives of Physical Medicine and Rehabilitiation, 2006 Vol 87, 504-509.
6. SalisburyS: Choy NL; Nitz J, Shoulder pain, range of motion, and functional motor skills after acute tetraplegia. Archives of Physical Medicine and Rehabilitiation, 2003 Vol 84, 1480-1485.
7. Collinger JL; Boninger ML; Koontz AM; Price R; Sisto SA; Tolerico ML; Cooper RA, Shoulder Biomechanics During the Push Phase of Wheelchair Propulsion: A Multisite Study of Persons With Paraplegia. Archives of Physical Medicine and Rehabilitiation, 2008 Vol 89, 667-676.
8. Vogel LC; Krajci KA; Anderson CJ. Adults with pediatric-onset spinal cord injury: part 2: musculoskeletal and neurological complications. Journal of Spinal Cord Medicine, 2002; 25: 117-123.

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