Spasticity Diagnosis and Treatment in the United States – A Priority for our Aging Population

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Introduction

Spasticity is a velocity-dependent increase in stretch reflex associated with involuntary muscle over-activity [1], which manifests secondary to central nervous system injury or illness. In the absence of effective treatment, spasticity can result in severe complications, including pressure sores, skin breakdown, urinary tract infections (UTIs), and painful limb contractures. Additionally, spasticity may impair the ability of caregivers to provide assistance with activities of daily living, such as personal hygiene and dressing. Despite its negative health implications and the burden of care it presents, spasticity often remains undiagnosed and therefore, untreated.

Recent studies report 21-35% prevalence of spasticity in nursing facilities [2,3]; however, only 13% of subjects who received a positive diagnosis had spasticity or a related condition recorded in their medical records prior to study initiation [2]. In addition, diagnosed patients are commonly under-treated, even though multiple therapeutic options are available, such as neurotoxin injection and intrathecal baclofen (ITB). Indeed, a survey of Medical Directors at 11 long-term care facilities in the United States found that despite a reported spasticity prevalence of 33% at these facilities, only 55% reported access for their residents to neurotoxin injection and 18% to ITB [4]. This inability to access treatments which are routinely recommended by neurologists, and which are supported by public payers and most commercial insurance plans in the United States, is not an uncommon occurrence [3].

The trends of under diagnosis and under treatment of spasticity present serious and growing concerns in the movement disorder community. Failure to identify or treat spasticity results in avoidable hospitalization, increased care burden for both professional and unpaid caregivers, and decreased quality of life for patients [5,6]. Given that spasticity is relatively easy to treat and prescribed therapies are safe and efficacious, even in patients with multiple comorbidities and concomitant medications, the current failure to provide patients with routine care for spasticity is concerning.

Impact of Variable Etiology on Spasticity Diagnosis

One factor confounding the issue of spasticity diagnosis is its variable etiology. Whilst spasticity is routinely diagnosed in patients with cerebral palsy and multiple sclerosis, with symptoms present in approximately 85% and 67%, respectively [7], spasticity caused by other neurological illness or injuries, such as spinal cord injury (SCI), traumatic brain injury (TBI), and stroke, is not as well characterized. Subsequently, spasticity is often overlooked as the more severe comorbidities associated with these injuries are prioritized for treatment. In addition, high variability in the elapsed time between illness or acute injury and onset of spasticity symptoms confounds diagnosis [8,9].

The incidence of SCI is reported to be around 40 per 1 million in the United States, or 12,000 new cases per year, and an estimated 259,000 presently live with traumatic SCI. Studies have indicated as many as 68% of those people have some level of spasticity [7]. The most common causes of SCI are vehicle accidents (39.08%) and falls (29.54%) [10]. Given that life expectancy of paraplegic and motor functional SCI patients is close to normal, the burden and cost of spasticity-related care for these patients is significant.

The Center for Disease Control and Prevention (CDC) reports approximately 2% of Americans have experienced TBI, with the leading cause being falls (35.1%). In the elderly, falls are responsible for 60.7% of all TBI [11]. To date only one small study has been conducted to assess the prevalence of spasticity in this population, which found that 34% of patients exhibited spasticity at 1 year post injury [12].

Approximately 795,000 people have a stroke in America each year, with around 610,000 of those reported to be the first incidence of stroke [13]. Research into spasticity prevalence in first stroke survivors indicates that between 20-43% may experience some form of spasticity as a result of the injury [8,9,14]. A conservative estimate suggests more than 1.4 million Americans have spasticity associated with a stroke and that 32% of those could benefit from a goal-directed spasticity treatment plan [7].

Challenges of a Changing Care Model for Spasticity Diagnosis

Another obstacle for spasticity diagnosis is the changing care model in the US. Following the Olmstead decision in 1999 regarding the enforcement of the “integration mandate” in Title II of the American Disability Act, greater emphasis has been placed on transitioning care away from institutions and into the community. Data collected in 2015 by the National Alliance for Caregiving and the AARP Public Policy Institute found the prevalence of unpaid caregiving in America to be 18.2% (43.5 million), and unpaid care is provided to 83% of recipients in their own home or the home of a relative [15]. With a predicted 54 million Americans requiring some level of daily care, a calculated 68% of those cared for in their own home or the home of a relative receive some portion of their care from an unpaid caregiver.

This move towards care in the community increases the likelihood that spasticity patients will be cared for in their home or the home of a relative. A recent study in Germany assessing the prevalence of post-stroke spasticity identified that only 31% of patients with severe spasticity (Modified Ashworth Scale score >2) were living in a group home or care facility at 16 weeks post-injury [16], and it is probable that similar circumstances would be observed in the US. The absence of trained care provision in many situations may hinder formal
identification of spasticity, and as the time of spasticity onset post-injury as well as its presentation can be variable [8,9], it is likely that post-injury follow up will not identify spasticity. In addition, with the majority of spasticity care administered through University outpatient clinics, transition to community-based care may present a barrier to treatment for those in rural areas.

Age-Associated Spasticity Risk

Looking to the future, under diagnosis and subsequent under treatment of spasticity presents a serious concern. The US population is rapidly aging, elevating the number of those at risk for age-related neurologic illness or injury. In 2012, there were an estimated 43.1 million people aged 65 and over in the US (14.1%), and this population is projected to nearly double by 2050 (83.7 million) [17]. The CDC reports that one third of elderly people fall each year. With falls responsible for more than half of all TBI and a reported 74% of all SCI [18] in this population, it is very likely that there will be an ever increasing population with spasticity. Adults aged 65 and over make up more than 65% of hospitalized stroke patients [19], and despite studies reporting a decline in stroke prevalence [20], it is likely that the expanded elderly population will subsequently lead to an increased incidence of stroke and post-stroke spasticity. The economic and social burden associated with untreated spasticity is already high and is likely to rise significantly as our population ages.

Future Research: Advancing Methods for Improving Diagnosis and Treatment of Spasticity

Improving diagnosis and treatment of spasticity is a challenging task, but one that must be considered a priority. There have been few recent diagnostic advances; the ‘gold standard’ has long been a physician’s history, examination, and impression, and therefore open to subjectivity - a problem that these authors are actively seeking to address. The challenges presented by an aging population and the transition away from institutional care will serve to exacerbate the flaws in our current practice, therefore it is imperative that the model for spasticity diagnosis and treatment evolves to better serve the needs of those afflicted. In order to do this, future research perspectives must address the following key barriers to improving diagnosis and treatment of spasticity: a) physician, caregiver, and patient spasticity education, b) improving referral for spasticity consultation, c) improving diagnostic methods and rates, and d) increasing treatment availability and access. Focused efforts to advance these key areas and integrate these approaches in normal practice will lead to the much-needed improvement in the standard of care for spasticity for millions of Americans living with this treatable condition.

Author Contribution

L.S, T.H, and D.C conceived the commentary. L.S, T.H, L.H, and A.D.C performed literature review and background research. L.S, A.D.C, and M.H developed the structure of the commentary. All authors contributed to analysis of under diagnosis and under treatment in spasticity and development of future research perspectives. L.S. prepared the manuscript. T.H, L.H, A.D.C, M.H, and D.C edited the manuscript.

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