Secondary Health Conditions and Health Status among Persons Living with Paralysis: A Cross-Sectional Population Study

Running Title: Secondary Health Conditions and Paralysis

Authors: Dixon-Ibarra, A., Livaudais, W., Higgins Tejera, C., & Krahn, G.

Corresponding Author : Alicia Dixon-Ibarra, PhD, MPH Oregon State University
Email : alicia.dixon-ibarra@oregonstate.edu
Phone : 814-934-0757

West Livaudais, MTS, MPH, Oregon Health & Science University
Cesar Higgins Tejera, MD, PhD candidate, University of Michigan
Gloria Krahn, PhD, MPH, Oregon State University

Background:

Understanding the prevalence of secondary health conditions (SHCs) and their relationship to health status can inform optimal clinical care for persons with paralysis. To date, population-based analyses on these indicators have been lacking.

Objectives:

To assess (i) the prevalence, severity and duration by causal conditions of paralysis in a national US adult population; (ii) SHCs by causal condition of paralysis; and (iii) how SHCs, severity and duration of paralysis relate to overall health status.

Design:

Cross sectional, population-based study, with negative binomial regression analyses.

Data Source:

Secondary data from a nationally representative sample of adults with paralysis. The U.S. Paralysis Prevalence and Health Disparities Survey is a random digit-dial survey of over 70,000 households to identify 1,305 households with a person with paralysis as defined by movement difficulty.

Participants:

1216 adults with paralysis.

Measurements: Self-reported paralysis, severity of functional limitations, SHC checklist, self-reported health, and days of poor physical health in the last 30 days.

Results:

Prevalence of paralysis is 1.7% of the population, caused by cerebral palsy (6.3%), multiple sclerosis (19.3%), spinal cord injury (25.7%), stroke (35.6%) and other causes (13.0%). Respondents reported a mean of 3.8 SHCs (from 9), with number and nature of SHC varying by cause. Severity of paralysis and number of SHCs were significantly related to fair/poor health status and number of poor health days in past month; duration of paralysis did not relate to health status. Younger age (<45 years) and greater annual income (>$50,000) showed protective association with health.

Limitations: self-report survey and low prevalence population

Conclusion: People with paralysis experience a number of secondary conditions that, if prevented, or managed well, can improve their overall health.

Primary Funding Source: None.

Introduction

Functional paralysis is much more prevalent in the United States than previously thought, affecting ~1.7% of the adult population (5.4M), with the majority of persons affected (72%) being between the ages of 18-64 (White & Cahill, 2014)(1). Many people with paralysis report poorer health than the general population. (Krahn, Suzuki, & Horner-Johnson, 2009; Krause & Saunders, 2011; Noonan, Kopec, Zhang, & Dvorak, 2008; Nosek et al., 2006). This poor health may be improved through better understanding of secondary health conditions (SHCs) and their effect on overall health of people with paralysis.

Paralysis can be caused in numerous ways across the life-course. For some people, the onset of paralysis relates to a condition manifest at birth and is relatively stable (e.g., spina bifida, cerebral palsy). For others, paralysis is the result of a progressive neuromuscular condition that worsens over the life course (e.g., multiple sclerosis, Friedreich's ataxia). Paralysis can have sudden onset, such as through a traumatic event (e.g., spinal cord injury (SCI), traumatic brain injury, stroke).

Secondary health conditions (SHC) are defined as physical or psychological health conditions that occur as a result of the primary disabling condition, are preventable or manageable, and negatively impact the health of the individual (IOM, 1991; Jensen et al., 2012; Rimmer, Chen, & Hsieh, 2011). Efforts to standardize measurement of SHCs in people with physical disabilities have identified a relatively brief list of common SHCs to consider (e.g., Ravesloot, Seekins & Walsh, 1997; Kalpakjian, Scilza, Forchheimer & Toussaint, 2007). The accumulation and interaction of SHCs over time can further destabilize health. For example, spasticity contributes to the development of contractures, chronic pain (Dalyan, Sherman, & Cardenas, 1998), and aggravate sleep problems (Vega et al., 2019), which can further . Despite many SHCs being preventable or manageable, they are primary contributors to hospital emergency departments visits, rehospitalizations, and institutionalization for people with SCI (Guilcher et al., 2013; Savic, Short, Weitzenkamp, Charlifue, & Gardner, 2000).

Duration of paralysis impacts a person's health, influencing how SHCs accumulate and interact over the life-course. Severity of paralysis influences an individual’s functional abilities and independence, with more severe paralysis believed to impact health more negatively (Irwin, Arthur, Mullins, & Hart, 2004). The relationship between duration of paralysis and SHCs has not been established (e.g., Ravesloot & Seekins, 1997). Paralysis duration may have a linear negative impact on health through increased risk of developing SHCs. Alternatively, people may learn to cope with their mobility limitation and demonstrate improved health the longer they live with paralysis (Dixon-Ibarra, Krahn, et al., 2016).

Underlying conditions causing paralysis may influence health directly (e.g., other conditions like seizures associated with the primary condition and indirectly (e.g., age at onset). People with relatively stable, congenital paralyzing conditions (e.g., CP, spina bifida) can develop positive coping mechanisms to their functional limitations (Holmbeck & Devine, 2010; Lindsay, 2016). Alternatively, paralyzing conditions that are degenerative (e.g., multiple sclerosis) disrupt one's "normal" functionality and require continual adaptation (Bucks et al., 2011; King, Duke, & O'Connor, 2009). Conditions like spinal cord injury and TBI have acute onset that require immediate and extensive adjustment (Cao, Massaro, Krause, Chen, & Devivo, 2014; Kennedy & Garmon-Jones, 2017; Kishi & Robinson, 1996). Onset of paralysis due to stroke is also typically acute and more common among older adults in whom age-related comorbidities may limit the ability to adjust (Field, Jette, & America, 2007).

Data from the U.S. Paralysis Prevalence and Health Disparities Survey provides the first opportunity to examine SHCs and health relationships with a nationally representative sample. Prevalence of paralysis as assessed by this survey has been reported previously (Armour et al, 2016). The present study addressed three research objectives. The first objective is to determine the prevalence of causal conditions of functional paralysis in the U.S. adult population and assess how cause relates to severity and duration of paralysis, and demographic characteristics. The second objective assesses the number and nature of SHCs experienced among persons with the most common causes of paralysis. Nine secondary health conditions are examined: abnormal muscle movement, accidental injury, autonomic dysreflexia, contractures, pain, pressure sores, sexual dysfunction, sleep disturbance, and urinary tract infections. The third objective is to determine how SHCs, severity of paralysis, and duration of paralysis relate to overall health for each of the primary causes of paralysis. The study addresses how the number of SHCs, severity of paralysis, and duration of paralysis relate to two indices of health—self-rated health and number of reported days of poor physical health among people with paralysis.

Methods

Data Source & Study Participants.

This cross-sectional population study was conducted using secondary data from the 2013 telephone-based U.S. Paralysis Prevalence and Health Disparities Survey (PPHDS). The PPHDS was developed through a cooperative funding agreement by the Centers for Disease Control and Prevention with the Christopher and Dana Reeve Foundation. A consensus conference of over thirty paralysis and epidemiology experts developed a functional case definition of paralysis as "difficulty moving arms or legs" due to a condition of the central nervous system (Fox, Krahn, Sinclair, & Cahill, 2015).

Respondents answering “yes” were asked to identify the cause of the difficulty from a list of medical conditions. The case identification process was deliberately broad to include physical limitations attributable to multiple causes.

Participants also answered questions on: SCI validation, severity of functional limitation due to paralysis, general health, secondary health conditions, and utilization of health care. Items for the survey were derived from nationally normed surveys in selected domains: American Community Survey (ACS), Behavioral Risk Factor Surveillance System (BRFSS), Survey of Income and Program Participation (SIPP), National Health Interview Survey (NHIS), and National Health and Nutrition Examination Survey (NHANES). Questions went through extensive cognitive testing, focus group feedback for understandability and clarity, pilot testing, and field implementation (Fox et al., 2015).

Measures

The survey was conducted by a national survey organization and involved contacting 70,458 households to identify 1,305 households with a person with paralysis.16 Both land lines and cellular phone numbers were used. Response rate for completion of the survey was 21.1%, which compares favorably with other national telephone surveys (e.g., Behavioral Risk Factor Surveillance System 2014; Summary Data Quality Report, 2015; Pew Research Center, 2012).

Demographic variables included age, sex, race, education, income, and marital status. Primary variables of interest included: cause of paralysis, severity of paralysis, duration of paralysis, and number and nature of SHCs associated with the paralysis. For this study, the four most common causes of paralysis were used in analyses (i.e., cerebral palsy, spinal cord injury, multiple sclerosis, and stroke) with an additional “other” category for participants with less common causes. The other category contains over 30 causes of paralysis with small sample sizes including cancer, arthritis, amputation, spina bifida, Guillain-Barre syndrome, and Parkinson’s. Severity of paralysis was assessed as a composite scale ranging from values of 0 to 7. The score includes the sum across seven questions (‘yes’ = 1, ‘no’ = 0) addressing serious difficulties with walking or climbing stairs; difficulty with dressing or bathing; serious difficulty concentrating, remembering or making decisions; difficulty doing errands alone such as visiting a doctor’s office or shopping; or needing help from other persons in eating; using the toilet; or getting around inside the house

The presence of SHCs was reported if the participant affirmed they “ever had” the condition. SHCs included: contractures (i.e., loss of joint motion), injury as a result of loss of sensation (i.e., cut, burn, broken bone), abnormal muscle movement (i.e., spasticity, uncontrolled jerky movement, or low muscle tone), pain, sleep disturbances (i.e., difficulty falling asleep, staying asleep, staying awake during the day, waking up early), urinary tract infections (UTI), autonomic dysreflexia (i.e., high blood pressure from overreaction of the involuntary (autonomic) nervous system), and difficulty with sexual function. The number of SHCs was assessed as a composite score ranging from 0 to 9, where the duration of paralysis was assessed as the number of years reported living with paralysis.

The first health outcome variable was self-rated health: “In the past 30 days, would you say your general health is: excellent, very good, good, fair, or poor,” and was coded dichotomously (good/very good/excellent v. fair/poor). This categorization is consistent with its typical use in population studies and is supported by comparability of findings based on dichotomous or categorical outcomes (Manor, Matthews, & Power, 2000). The second health outcome variable was the number of reported days of poor physical health during the last 30 days. To utilize the most data in analyses, this variable was operationalized as a count variable with values ranging from 0 to 15+. There were few data points beyond 15 days. This study used de-identifiable data and was exempt from institutional review.

Statistical Analyses

To reflect the U.S. population, sample weights used a process of iterative proportional fitting (IPF) in which the sample was balanced to match known adult-population parameters based on the most recent March Supplement of the U.S. Census Bureau’s Current Population Survey, including age, sex, race, census region, education and race/ethnicity. As the PPHDS was conducted on both land lines and cell phone numbers, the second stage included additional weighting to account for the distribution of phone service in the general population (cell phone only, cell phone mostly, landline only, and mixed users) (Fox et al., 2015).

Proportions, confidence intervals, and associated p-values were calculated for cause of paralysis, duration, severity, SHCs, and demographic variables. Survey design-based F-tests (a corrected version of Pearson χ^2 statistics) examined the association between the different causes of paralysis and categorical covariates of age (<45, 45-54, 55-64, 65+ years), sex (male, female), race (white, non-white), income (<\$15,000, \$15,000-\$50,000, >\$50,000), education (<high school, high school graduate, college graduate), and marital status (single, married, separated/divorced, widow). For continuous variables, ANOVA tests determined mean differences in duration of paralysis, number of secondary health conditions, and severity of paralysis.

To assess the relationship of SHCs with health outcomes, negative binomial regression analyses were calculated to determine associated risk of two outcome measures: poor self-rated health and number of poor physical heath days. These were predicted by the following variables: cause of paralysis, duration of paralysis, severity of paralysis, and number of secondary health conditions. The negative binomial model was used to relax the assumption of over-dispersion of the Poisson model, a relevant feature depicted in the data. Two different regression models for each outcome were built: a “complete data case” model with all variables reported by respondents and, as a sensitivity analysis, a “multiple imputation” model where variables were imputed to reduce the number of people omitted from the analyses to reduce bias. Cerebral palsy served as the reference group category for analyses.

The survey had greater than 11% missing data when conducting the list-wise deletion model. Variables with the highest total missingness include income (14.9%), autonomic dysreflexia (10.7%,) and sexual function (11.4%). Since we could not assume data were missing completely at random, a multiple imputation negative binomial model was computed and compared to the complete data case analysis. STATA 15 was used to create the multivariate imputation chained equation (MICE) for dealing with the missing data. There were 20 imputed data sets in the imputed negative binomial model including the following variables: sex, income, marital status, severity, duration, and number of SHCs. The convergence of the models was graphically analyzed.

Results

Demographic characteristics of the sample.

From the national representative sample, about 1.7% of persons report paralysis with 35.6% experience paralysis due to stroke, 19.3% multiple sclerosis, 25.7% spinal cord injury, 6.3% from cerebral palsy, and 13.0% from other conditions. Table 1 presents the demographics of this nationally representative sample of 1216 adults by cause of paralysis. Across all causes, respondents were largely 45 years or older (76.4%) and white (82.4%); nearly evenly distributed between males and females, (47.4%, 52.5%), with just less than half being married (44.1%). Most had completed a high school education (62.2%) or college degree (22.9%), and 76.6% had annual incomes between $15,000 and $49,000. Observed differences across diagnostic groups were evident across the demographic characteristics. Almost 60.6% of respondents with CP were under age 45, while 48.6% of respondents who were post-stroke were over age 65. More than 66.1% of respondents with MS were female, while other conditions were more equally distributed across sexes. The stroke group was almost one-quarter non-white (22.6%), while MS was 9.8% non-white. Respondents with MS had the highest percentage of being married (52.4%); CP of being single (36.9%); stroke of being widowed (12.6%). Consistent with education level, those with MS had higher proportions of individuals making over $50,000 annually (38.9%), while 26.2% of those with CP made less than $15,000 annually.

Duration and severity of paralysis. The mean number of years living with paralysis is 16.7 (95%CI, 15.7-17.7) with the longest duration among persons with CP at 31.3 (95%CI, 26.6- 36.1) and shortest for stroke at 9.6 (95% CI, 8.3-10.9). High rates of limitation were reported across all conditions for ‘difficulty bathing/dressing’ (54.0%), ‘difficulty remembering’ (49.0%), and ‘difficulty performing errands’ (64.3%), but relatively fewer difficulties with feeding and toileting. The mean severity of limitation across groups ranged from M= 2.8, (95%CI, 2.6- 3.1) for persons with MS to M=3.4, (95%CI, 3.2-3.6) for persons with stroke. The pattern of limitations varied across the cause of paralysis.

Health characteristics of the sample

Prevalence of secondary health conditions. The mean number of SHCs from the list of nine conditions was 3.8 (95%CI, 3.7-4.0) across all causes, with people with SCI reporting the most (M= 4.6, 95%CI: 4.3, 4.9) and persons with CP the fewest (M=2.6, 95%CI: 2.3, 3.5). The most prevalent secondary health conditions among all causes of paralysis were sleep disturbances (70.3%), pain (68.6%), abnormal movement (63.1%), and UTIs (50.6%). Pressure sores (PS) were the least prevalent (15.4%).

Health status. Among all persons with paralysis, the average days of self-reported poor health in a month was 8.3 (95%CI, 7.9-8.8). Those with SCI had the highest average days of reported poor health (M=9.9, 95%CI, 9.1-10.8); those with CP the fewest (M=4.6, 95%CI, 2.9-6.2). Across the entire sample, 59.4% reported having fair or poor health, with those with MS, SCI, and stroke ranging between 61.5%-63.5% reporting fair/poor health status and those with CP lower at 26.4%.

Regression models of health status by characteristics of paralysis

In Table 3, complete data case (Model 1) and multiple imputation models (Model 2) yielded highly similar results across both examined health outcomes. For more comprehensive estimates based on all respondents, the imputed model (Model 2) will be described. Cumulative incidence ratios (IR) are provided in Table 3 from count-based regression models. Results are considered significant at alpha level less than 5%.

Significant associations were observed for self-reported health status, with higher rates of fair/poor health across causes of paralysis when compared to those with CP (Multiple Sclerosis IR=2.24; 95% CI=1.39,3.59; Spinal Cord Injury IR=1.79; 95% CI=1.11,2.88; Stroke IR=1.84; 95% CI=1.14,2.97). These associations were also statistically significant for the outcome of days of reported poor health in the past month except for stroke, which was not significantly higher than CP.

Severity of paralysis and number of SHCs were significantly associated with poor health status (severity IR=1.09; 95% CI=1.06, 1.12; SHCs IR=1.09; 95% CI=1.06, 1.13) and days of reported poor health in the past month (severity IR=1.08; 95% CI=1.04, 1.13; SHCs IR=1.12; 95% CI=1.08, 1.16). Duration of paralysis was not associated with health status in the current sample.

Among the covariates, age, specifically between 45-64 years, was associated with poor self-reported health when compared to those < 45 years (45-54 years IR=2.24; 95% CI=1.39,3.59; 55-64 years IR=2.24; 95% CI=1.39,3.59). Further, when compared to those who made <$15,000 annually, persons making over $50,000 annually showed a protective association with self-reported health status (IR=0.81; 95% CI=0.67, 0.99). All other covariates of race/ethnicity, education, and marital status were not significantly associated with self-reported health. There were no covariates associated with days of reported poor health in the past month.

Discussion

This paper is the first known evaluation of prevalence of SHCs in a nationally representative sample of U.S. adults with functional paralysis. As such, these findings are unique in their generalizability to the entire U.S. population. With respect to the first objective, findings indicate that 1.7% of the U.S. adult population is living with paralysis as defined by “difficulty moving arms or legs.” Severity of paralysis indicates that participants reported difficulty with an average of about three activities of daily living, with differences in nature of limitations evident across causes of paralysis. As expected, duration of disability is longer for those with early onset paralysis (e.g., cerebral palsy) compared with later life onset (e.g., stroke). Age differs across the causes of paralysis, with people with CP having higher proportions in younger ages (67.5% <45 years) and people with stroke generally being older (41.4% > 65 years). Consistent with other literature, a preponderance (70.5%) of persons with multiple sclerosis are female (Eikelenboom, Killestein, Kragt, Uitdehaag, & Polman, 2009; Ghezzi et al., 1997; Maghzi et al., 2010; Orton et al., 2006). Education and employment also differ across groups, with adults with MS tending to have more education and higher incomes. Age at onset of paralysis and overall age are likely factors in these observed differences in education and income; these, in turn, contribute to a life of disability-related poverty that is well-documented (United Nations, 2018).

Regarding the second study objective, the number and nature of SHCs varied across the four causes of paralysis. Overall, adults with paralysis experience high rates of sleep disturbance (70.3%), pain (68.6%), abnormal muscle movements (63.1%), and urinary tract infection (50.6%) regardless of causal condition. A surprisingly high proportion of respondents across groups reported experiencing autonomic dysreflexia, a condition typically attributed primarily to SCI. Interviewers defined autonomic dysreflexia as “high blood pressure resulting from overstimulation to the nervous system.” The endorsement rates of 13.7% (CP) to 31.8% (SCI) suggest that respondents used a more general interpretation than a clinical definition of this secondary condition. Adults with SCI experienced a higher total number of SHCs while those with CP experienced fewer. When comparing across groups, persons with SCI had higher proportions of pressure sores, injury due to loss of sensation, contractures, pain, autonomic dysreflexia, and sexual dysfunction.

Regarding the third study objective, regression analyses demonstrate that even after controlling for significant differences in demographics, total number of SHCs and overall severity of paralysis are significantly related to poor health status across causes of paralysis. Previous studies have documented the negative impacts of SHCs on persons with disabilities, ranging from poor quality of life to premature mortality (Guilcher et al., 2013; Kinne, Patrick, & Doyle, 2004; Krause & Saunders, 2011). The present findings emphasize the importance of preventing and managing SHCs as a way of promoting overall health of persons with paralysis. While severity of paralysis may not be modifiable, its effect on health may be mitigated if SHCs are prevented, diagnosed early, and managed well.

Previous studies have demonstrated inconsistent effects of duration of paralysis (as distinct from age) on overall health. While duration of paralysis has been correlated with total fat mass and bone density (Dionyssiotis, et al, 2008; Jensen et al, 2013) and risk for hypertension and cancer in adults with SCI (Saunders et al, 2015), other studies have demonstrated that personal adjustment following paralysis is more important than age or duration of injury (Krause & Crewe, 1987). People aging *with* paralysis have reported better health than those with later onset who age *into* paralysis (Dixon-Ibarra, Krahn, et al., 2016). The present findings from a relatively large, national sample of adults with paralysis failed to demonstrate a linear relationship between duration of paralysis with self-reported health or number of days of poor physical health. It is possible that the relationship of duration of paralysis with health outcomes is non-linear, that inconsistencies relate to the outcome measures used in different studies, that duration of disability is confounded by cause of paralysis, or that the tremendous changes in medical and rehabilitation treatments over the past decades confound recent treatment options with duration making it difficult to disentangle their relative effects in a cross-sectional design. Future research could test these alternative explanations in examining the effect of duration of paralysis on health.

While not examined in this study because of power limitations, SHCs are not presumed equivalent in their impact on health. For instance, while sleep disturbances can significantly reduce one's quality of life and have long-term impact on health, a pressure injury, urinary tract infection or autonomic dysreflexia can quickly become life-threatening if not treated (Allman, 1997; Gorecki et al., 2009; Lyder & Ayello, 2008; Spilsbury et al., 2007). The relative impact of different SHCs on health is an important area for future attention.

Strengths of the present study are use of high-quality, nationally representative data and survey weights to yield population estimates. Further, multiple imputation modeling analyzed the impact of missing data in the relationships on health outcomes to address selection bias. Study limitations include self-reported health variables not confirmed by medical assessment. Secondly, some SHCs may be under- or over-reported. SHCs that are considered socially sensitive, such as sexual dysfunction, may have been under-reported. Limited sample size restricted our models to fewer variables and covariates.

This study is intended to provide foundational knowledge on SHCs and their relationship to health status among persons with paralysis. These findings can complement the in-depth data of clinical studies by providing prevalence estimates to inform prevention, treatment, and management of SHCs. The next step is to better understand how SHCs influence health and healthcare utilization. Future research in this area could examine the relative impact of different SHCs on health. Do sleep disturbances influence health status more than contractures? Do UTIs lead to greater health care utilization than sexual dysfunction? Answering these questions can better equip clinicians supporting persons with paralysis and inform public health on ‘high priority’ SHCs for health promotion. Future studies could investigate how SHCs, severity, and duration influence mental health status.

Living a healthy life for people with paralysis includes the prevention and/or reduction of SHCs (Lollar & Andresen, 2011). The implication for clinicians is that augmenting care plans with health promotion materials, supportive-vigilance resources and assistive technology, proactive management and therapy, and use of peer supports or community health workers with lived-experience with paralysis could reduce the negative impact of SHCs on health.

References

Adriaansen, J. J., M.D. Ph.D, & E. (2016). . *Journal of Rehabilitation Medicine, 48*, 853-860. doi:10.2340/16501977-2166Allen KJ, Leslie SW. Autonomic Dysreflexia. [Updated 2018 Jul 13]. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2018 Jan-. Available from: https://www-ncbi-nlm-nih-gov.liboff.ohsu.edu/books/NBK482434/

Allman, R. M. (1997). Pressure ulcer prevalence, incidence, risk factors, and impact. *Clinics in Geriatric Medicine, 13*(3), 421-436. Retrieved September 3, 2017, from http://europepmc.org/abstract/med/9227937

Behavioral Risk Factor Surveillance System 2014 Summary Data Quality Report. (2015, July 29). Retrieved February 29, 2016, from https://www.cdc.gov/brfss/annual_data/2014/pdf/2014_dqr.pdf

Christopher and Dana Reeve Foundation (Ed.). (2009). One Degree of Separation. Retrieved September 3, 2017, from https://www.ncart.us/uploads/userfiles/files/one-degree-of-separation.pdf

Dixon-Ibarra, A., Krahn, G., Fredine, H., & Cahill, T. (2016). Health of adults aging with paralysis: National paralysis survey 2012-2013. Journal on Disability and Health.

Fox, M. H., Sc.D., Krahn, G. L., Ph.D., M.P.H., Sinclair, L. B., M.P.H., & Cahill, A., Ph.D. (2015). Using the international classification of functioning, disability and health to expand understanding of paralysis in the United States through improved surveillance. *Disability and Health Journal, 8*(3), 457-463. doi:10.1016/j.dhjo.2015.03.002

Gorecki, C., M.Sc., Brown Professor, J. M., Nelson, E. A., Ph.D., Briggs, M., Ph.D., Schoonhoven, L., Ph.D., Realy, C., Ph.D., . . . Nixon, J., Ph.D.. (2009). Impact of Pressure Ulcers on Quality of Life in Older Patients: A Systematic Review. *Journal of the American Geriatrics Society, 57*(7), 1175-1183. doi:10.1111/j.1532-5415.2009.02307.x

Jensen, M.P., Molton, I.R., Groah, S.L., Campbell, M.L., Charlifue, S., Chiodo, A., et al. (2012). Secondary Health Conditions in Individuals Aging with SCI: Terminology, Concepts and Analytic Approaches. *Spinal Cord*, 50,373–378.

Krause, J. S., Ph.D., & Sanders, L. L., Ph.D.. (2011). Health, Secondary Conditions, and Life Expectancy After Spinal Cord Injury. *Archives of Physical Medicine and Rehabilitation, 92*, 1770-1775. doi:10.1016/j.apmr.2011.05.024

Lollar, D., & Andresen, E. (2011). Public health perspectives on disability: epidemiology to ethics and beyond. New York: Springer. doi:10.1007/978-1-4419-7341-2

Lyder, C. H., & Ayello, E. A. (2008). Pressure Ulcers: A Patient Safety Issue. In *Patient Safety and Quality: An Evidence-Based Handbook for Nurses* (pp. 1-267-1-299). Rockville , MD: Agency for Healthcare Research and Quality (US). Retrieved September 3, 2017, from https://www.ncbi.nlm.nih.gov/books/NBK2650/.

Pew Research Center. (2012, May 15). Assessing the Representativeness of Public Opinion Surveys. Retrieved September 5, 2015, from http://www.people-press.org/2012/05/15/assessing-the-representativeness-of-public-opinion-surveys/

Rimmer, J. H. (1999). Health Promotion for People With Disabilities: The Emerging Paradigm Shift From Disability Prevention to Prevention of Secondary Conditions. *Physical Therapy, 79*(5), 495-502. Retrieved September 3, 2017.

Spilsbury, K., Nelson, A., Cullum, N., Iglesias, C., Nixon, J., & Mason, S. (2007). Pressure ulcers and their treatment and effects on quality of life: hospital inpatient perspectives. *Journal of Advanced Nursing, 57*(5), 494-504. doi:10.1111/j.1365-2648.2006.04140.x

White, G. W., Ph.D., & Cahill, A., Ph.D. (2014). 2014 Bridging Meeting On Paralysis, Other Physical Disabilities and Health Disparities: Translating Data Into Policy and Practice. Address.

Wilber, N., Mitra, M., Klein Walker, D., Allen, D., Meyers, A. R., & Tupper, P. (2002). Disability as a Public Health Issue: Findings and Reflections from the Massachusetts Survey of Secondary Conditions. *The Milbank Quarterly, 80*(2), 393-417. Retrieved September 3, 2017.

World Health Organization. International classification of functioning, disability and health: ICF. World Health Organization; 2001.