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Abstract

Background: Guillain-Barre Syndrome is a condition resulting from the immune system attacking the myelin in the peripheral nervous system and can lead to acute peripheral polyradiculoneuropathy. While an acute condition, symptoms can persist long after neurological recovery has occurred. Unfortunately, the effects of these prolonged issues on the patient are often overlooked. **Purpose:** The purpose of this case report is to propose considerations for measuring outcomes during physical therapy for an individual diagnosed with Guillain-Barre Syndrome in an outpatient orthopedic setting. **Case Description:** A 38-year-old male presented to physical therapy seven weeks after acute onset of clinically diagnosed Guillain-Barre Syndrome. The patient sought treatment for his right shoulder pain in addition to low back pain and generalized weakness. Interventions were focused on strength and neuromuscular control of his right shoulder, core and hip stability, and functional endurance for his generalized weakness. **Outcome Measures:** The QuickDASH, Numerical Pain Rating Scale (NPRS), and a functional outcome of returning to work were utilized to measure improvement during physical therapy. There was noted variability at re-assessments, resulting in difficulty determining improvement. The use of additional outcome measures for fatigue and quality of life were proposed, including the Fatigue Severity Scale and Medical Outcome Short Form-36. **Discussion:** There is need for future research to identify an outcome measure that accounts for the variability of chronic symptoms in Guillain-Barre Syndrome and their effect on the individual.

Keywords: Guillain-Barre Syndrome; neurology; orthopedics; physical therapy; rehabilitation; outcome measures; QuickDASH

Introduction

Guillain-Barre Syndrome (GBS) is an uncommon condition when the immune system attacks an individual's peripheral nervous system [10]. The incidence of GBS is roughly 1-3 individuals per 100,000 in the population [5, 19]. Some studies indicate that the incidence is greater in older age, however, it does not exclude afflicting those of younger age as well [1]. Though causation is not confirmed, many cases of GBS follow an infection contracted by the individual, some studies citing two-thirds of GBS cases [19]. There are several different variants of the syndrome, but in North America the most common variant, accounting for 90% of cases, is called acute inflammatory demyelinating polyradiculoneuropathy (AIDP) [7, 19]. In the AIDP variant, the immune cells named macrophages and T-lymphocytes, target the Schwann cells in the peripheral nervous system with guidance from the activated complement system, damaging the myelin sheath of the peripheral nerves [5,19]. The specific mechanisms of the complement system in this pathogenesis are not definitive, however, the various hypotheses all result in the same myelin damage or demyelination [19]. The damage to the myelin sheath ultimately results in rapid onset, acute peripheral polyradiculoneuropathy, as the myelin is important for rapid nerve conductance [19]. Other variants of GBS seem to follow different mechanisms of pathogenesis.

Acutely, signs and symptoms of Guillain-Barre Syndrome, resulting from the damage and demyelination, can include the following: rapid onset of bilateral and symmetrical paresthesia, symmetrical paresis of extremities (and potential for respiratory manifestations from paresis), hypo- and/or areflexia, increased protein in cerebrospinal fluid with a normal white blood cell count, autonomic dysfunction, and pain. These signs and symptoms typically plateau within two to four weeks of the initial onset of symptoms, then begins the recovery and healing process [19]. Due to the rapid and progressive onset of symptoms, patients often find themselves in to see a physician quickly, and a diagnosis can be made by the clinical features, a lumbar puncture, nerve conduction studies, and electromyography, allowing for proper care to be administered [19].

Though many patients with GBS recover within 12 months, it is not uncommon for a sequalae to persist. Chronic pain, fatigue, and paresis are oftentimes experienced, affecting overall quality of life long after initial diagnosis and apparent healing has occurred. According to the literature, the presence of persistent fatigue does not appear to be related to concurrent residual neuromuscular deficits, as it can also persist beyond neurological recovery. It has been suggested that psychosocial components may contribute to this fatigue and vice versa, negatively affecting overall quality of life (QOL) [13, 18]. Unfortunately, the effects of these long-term residual issues are oftentimes overlooked after the acute phase of the syndrome.

Guillain-Barre Syndrome is not a diagnosis typically seen by many physical therapists in the outpatient orthopedic setting, which may present a challenge when providing care. There remains a void in high quality evidence when looking at the research regarding the effects of physical therapy interventions on individuals with GBS, more specifically for an individual no longer in the acute phase of the syndrome. This is compounded by neurological recovery oftentimes being the sole outcome being measured, while the residual symptoms of the syndrome are frequently overlooked. The effects and interactions of these residual problems of fatigue, pain, and decrease in QOL, in those affected by Guillain-Barre Syndrome are not fully understood, however could play a critical role in an individual's perception of recovery. These individuals, despite neurological recovery, face potential long-term disability, secondary to these chronic presentations. This may suggest the importance of tracking these as outcome measures within this population. The purpose of this case report is to discuss these challenges and their effect on measuring progress when providing physical therapy for an individual with Guillain-Barre Syndrome.

Case Description

Presentation/History (history obtained from patient interview)

A 38-year-old male presented to an outpatient orthopedic physical therapy clinic for the treatment of right shoulder pain, low back pain, and generalized weakness about seven weeks following his initial onset of clinically diagnosed Guillain-Barre Syndrome. The patient did not recall a recent history of illness or infection prior to the onset of his symptoms. However, he did mention that he had received his flu shot not long before, though could not provide a timeframe. He reported pain with reaching overhead and difficulty walking greater than one hour, secondary to weakness and pain in his low back and bilateral lower extremities. Prior to his hospitalization and subsequent rehabilitation, he worked in the restaurant business, requiring him to be on his feet for long durations. The patient's physical therapy goal was "to increase strength and tolerance to activity, while decreasing pain, so that he could return to work."

At his initial evaluation he gave the following history. About seven weeks prior, he presented to the emergency room after waking up from a night of sleep to parasthesia from the neck down and quadriparesis. Despite negative results from a spinal tap taken when he arrived at the hospital, he was clinically diagnosed with Guillain-Barre Syndrome due to his presentation of acute tetraplegia, parasthesia, and absent reflexes at bilateral upper and lower extremities. The patient was then admitted to an inpatient unit at the hospital for 6 days where he received intravenous immunoglobulin (IVIG) therapy. During this time, he received inpatient physical therapy daily, where he was trained to complete slide-board transfers to a wheelchair that he would self-propel. While negotiating his wheelchair, he began to experience right shoulder pain which did not resolve. He was then transferred to an inpatient rehabilitation hospital where he received both physical therapy (PT) and occupational therapy (OT) 3 hours per day, 6 days per week, for 2 weeks. During this time, he progressed from a wheelchair to ambulation with two-person assistance, though his right shoulder pain persisted. He was then discharged home with the ability to ambulate with a wheeled walker and contact guard assistance, provided by his wife and a gait belt. He then received home health PT for 2 more weeks, the first week also accompanied by OT. One-hour long sessions were completed two times per week, focusing on bilateral lower extremity strength and endurance for increased independence with functional mobility. Other past medical history included hypertension, for which he was on medication for, and upper gastrointestinal disease.

Examination and Evaluation

At his initial evaluation at outpatient physical therapy, two weeks following his discharge from home health physical therapy, the patient presented without an assistive device, ambulating independently, without signs of antalgia. Observation revealed forward head, forward shoulder posture, in addition to increased thoracic kyphosis and decreased lumbar lordosis. He reported right shoulder pain, 7/10 on the numerical pain rating scale (NPRS), and low back pain, 3/10 on the NPRS. He also completed the Quick Disabilities of Arm, Shoulder, Hand (QuickDASH) form. Testing of his right shoulder indicated weakness when compared to the left, in addition to positive testing to rotator cuff pathology, as indicated with positive Hornblower's sign, Lift-off test, Drop Arm test, and Empty Can test. He exhibited decreased thoracic extension with overhead arm movement. Grossly, his right shoulder strength testing, utilizing manual muscle testing (MMT), revealed gross strength of 4/5, weak when compared to the 5/5 testing on the left. His right shoulder range of motion (ROM) remained within functional limits and symmetrical to his left shoulder, though he reported pain with overhead movement. His pain was not associated with a painful arc. Palpation tenderness was noted just distal to his right acromion. His sacroiliac joint screening and hip provocation tests were negative, but further testing of his lumbar spine indicated hypomobility, associated with pain, with joint mobility assessment.

Decreased flexibility was noted with bilateral hip internal rotator musculature and hamstrings. General weakness of bilateral lower extremities noted with MMT, revealing 4+/5 strength.

Clinical Impression

Upon completion of the examination, the therapist concluded that the signs and symptoms of the patient's right shoulder, including weakness, palpation tenderness, rotator cuff pain referral pattern, and positive rotator cuff pathology testing were most consistent with rotator cuff tendinopathy, most specifically supraspinatus. The generalized weakness reported and assessed during the evaluation, most notably at bilateral lower extremities, and was determined to be residual from the patient's Guillain-Barre Syndrome onset and diagnosis almost seven weeks prior. It was determined he patient's report of low back pain was likely related to dramatic change in activity and marked increase in the supine and seated positions following his diagnosis, as his work required more standing and walking. Accounting for the patient's history of Guillain-Barre Syndrome and his progress with therapy thus far in the acute hospital, inpatient hospital, and home health setting, he was expected to have a fair to good prognosis in reducing his right shoulder pain, returning muscle strength and endurance, as well as improving his overall functional mobility and tolerance to activity.

Intervention:

The patient attended physical therapy at an outpatient orthopedic clinic 1-2 times per week, 30-minute visits, for 5 months to address pain, flexibility, gross lower extremity strength, rotator cuff and scapular strength, neuromuscular control, and muscular endurance. At the initial evaluation, posture education and a return to walking program for home was discussed to promote optimal positioning for the rotator cuff musculature and to improve muscular and cardiovascular endurance, respectively. This was revisited intermittently throughout his care to provide guidance and to assess tolerance. Frequent discussions were held regarding how frequently the patient should be completing his home and therapy exercises, as he regularly reported fatigue. He was encouraged to begin exercises every other day, monitor his response, and then inform us of his tolerance. The patient began, or arrived prior to, each session completing 5-10 minutes on the arm ergometer at a self-selected intensity, to increase blood flow and heart rate as a warm-up exercise.

Interventions for his right shoulder included soft tissue mobilization, trigger point dry needling, and joint mobilization to decrease pain and to optimize length tension of the musculature when appropriate. Rotator cuff and scapular strengthening and neuromuscular control exercises were introduced to his right upper extremity. Progressive strengthening exercises introduced over time were the following: progressive prone I/Y/T, side-lying external rotation, standing resistance banded external rotation and internal rotation in various amounts of abduction, scapular retractions, shoulder protractions, low rows, full can exercises, wall balls, and body blade exercises. Furthermore, the patient's lack of thoracic extension and mobility was addressed with joint mobilizations and exercises, including: foam roller thoracic extension, standing wall thoracic extension, pectoralis minor foam roller stretch, open books, and quadruped thoracic rotations.

Core and hip strengthening exercises included: hook lying transversus abdominus activation, prone leg lifts, progressive bridging, progressive bird-dog, sit-to-stands, clamshells, standing progressive four-way kicks, banded side-stepping, monster walks, supine 90/90 with lower extremity rotations, anti-rotational walk-outs, half-kneeling to standing lifts and chops, and planks.

His home exercise program consisted of various combinations of the above listed exercises, targeting the same objectives of gross bilateral lower extremity strength, right upper extremity strength, scapular strength and neuromuscular control, core and hip strength, and muscular flexibility. He

reported he was also completing cardiovascular exercise on his own on a recumbent bike. Moist heat was also used frequently, for reported pain relief.

Outcomes

The first re-assessment marked his progress approximately 3 months into his outpatient intervention reported here, with the second re-assessment marking his progress after approximately 5 months, though continued physical therapy in the outpatient clinic setting was anticipated.

Prior to the initial examination, the patient completed the Quick Disabilities of Arm, Shoulder, Hand (QuickDASH) form. It is a shorter questionnaire than the original DASH, to lessen the time and effort needed to complete. Despite this, it upholds an excellent correlation to the DASH (r=0.96 for musculoskeletal conditions, r=0.97 for chronic pain) [15]. It consists of 11 questions with a 1-5 point scale, (1 representing no symptoms/difficulty with activity and 5 representing extreme symptoms or unable to perform activity). The responses are then summed and averaged before being translated into the disability and symptom score (range 0-100), with a higher score indicating higher symptom report and disability and vice versa. The minimal detectable change (MDC) for a musculoskeletal condition is 11 points (11.2 for chronic pain) and the minimal clinical important difference (MCID) is 9-11.3 points (11.2 for chronic pain) [15]. It exhibits an excellent test-retest reliability (ICC=0.94 for musculoskeletal conditions and 0.90 for chronic pain) [15]. The QuickDASH was within the battery of orthopedic outcome measures that was utilized with all patients at the outpatient orthopedic clinic, and it was chosen due to the patient's right shoulder injury when negotiating his wheelchair earlier in his rehabilitation and his high report of right shoulder pain. The patient tallied a symptom and disability score of 25 out of 100 on the QuickDASH at the initial evaluation, 32 at first re-assessment and 36 at the second re-assessment (see Table 1). Change in QuickDASH score from the initial evaluation to the second re-assessment showed him with increased disability and symptom scoring that met the MDC for a musculoskeletal condition and was merely 0.2 points shy in meeting the MDC for a chronic pain condition. Interestingly, the patient's subjective history at the start of the second re-assessment indicated that he felt like his shoulder was "getting better" despite the QuickDASH indicating worsening disability.

The numerical pain rating scale (NPRS) is a 0-10 scale measuring an individual's perceived intensity of pain (0 representing no pain, 10 representing worst possible pain). This scale is quick and easy to use in clinic and is widely used in healthcare across the United States. The MCID ranging from 1-2.17 points in the chronic pain population, with an excellent test-retest reliability (r=0.79-0.92) with increasing number of ratings [14]. At the start of his outpatient care, the patient reported his right shoulder pain as 7/10 and his low back pain as 3/10. At his first re-assessment he reported 3/10 of his right shoulder and 1/10 with his low back pain. At the culmination of 5 months following initial evaluation, his NPRS score for his right shoulder was 2-3/10 and his low back pain was 9-10/10. At the first re-assessment, the MCID was achieved with both the right shoulder pain and the low back pain, however, at the second re-assessment, the patient's low back pain had markedly increased, also meeting MCID. Throughout his care, his NPRS ratings greatly varied, as he frequently reported "good days" and "bad days". The location of his pain also varied frequently, making it difficult to assess progress over time.

Self-reported function was also utilized to assess the patient's progress, specifically his return to working in the restaurant business (45-50 hour work week, 6 days/week). This functional activity was chosen because it was a goal of the patient to return to working as he had prior to his initial onset of Guillain-Barre Syndrome. At the initial evaluation, the patient had not yet retuned to work (0% return to work). At his first re-assessment, the patient had returned to work part-time, fulfilling 2-3 hours per work day (27-36% return to work). At his second re-assessment the patient had not yet returned to his

full schedule, however, was then working 5-6 hours per work day (67-72% return to work). Despite increasing his hours progressively, he stated that he required frequent rest breaks throughout the day.

At the second re-assessment, MMT was completed, revealing improved gross bilateral lower extremity strength of 5/5 (compared to 4+/5 initially) and gross right shoulder strength of 4+/5 (compared to 4/5 initially), possibly revealing partial neurological recovery or ongoing recovery.

Table 1. Outcome Assessments at Initial Evaluation and Re-Assessment

	Initial Evaluation (Outpatient)	Re-Assessment (~ 3 mo)	Re-Assessment (~5 mo)
QuickDASH	25	32	36
Pain (NPRS)	Right Shoulder: 7/10 Low Back: 3/10	Right Shoulder: 3/10 Low Back: 1/10	Right Shoulder: 2-3/10 Low Back: 9-10/10
Functional Outcome	Unable to work	Working 2-3 hrs/work day	Working 6-7 hrs/work day (frequent rest breaks)

As seen in the outcome assessments (Table 1), the patient's functional outcome, return to work, progressed with linear improvement in hours of work completed per work day. However, qualitatively, his return to work was accompanied by increased need for rest breaks throughout the day due to fatigue. The QuickDASH and the NPRS showed interesting outcomes. While the patient's numerical pain rating score for his right shoulder progressively lessened, his QuickDASH disability score increased. Simultaneously, the patient's numerical pain rating score for his low back showed great variability and was rated at its greatest perceived intensity at the latest re-assessment. This report of fatigue altering the quality of the patient's functional outcome, in addition to variability in pain intensity, and the unexpected increase in disability and symptom score for the right shoulder, revealed challenges in providing comprehensive metrics showing meaningful change for the patient.

Outcomes Considerations

The outcome assessments used for this patient show that there could be other factors affecting the variability exhibited. As stated earlier, chronic symptomology of Guillain-Barre Syndrome is widely ignored regarding outcome measurement for recovery. Their effects on the quality of life of these individuals may better inform us of meaningful change for a patient. There are several other standardized outcome measures that would have been appropriate to implement with this patient, specifically regarding fatigue and quality of life. Chronic fatigue is not uncommon in neuromuscular conditions, and high prevalence has been reported in individuals with Guillain-Barre Syndrome (M). Quality of life has also been linked to pain and fatigue in this population and could provide important information regarding recovery.

The Fatigue Severity Scale (FSS) is a questionnaire measuring the effect and severity of fatigue in an individual. A patient is asked to select between 1-7 (strongly disagree to strongly agree) regarding 9 statements. A rating of >5 is typically accepted as indicating severe fatigue [13]. Scoring ranges from a minimum of 9 and maximum of 63, the larger the number indicating the greater effect/severity of fatigue on the individual. It has been found that individuals with GBS score higher than healthy individuals [9]. The use of an outcome measure that measured the patient's fatigue would have been appropriate and may have provided additional information on the variance of his NPRS reports, especially given the high correlations seen between fatigue and pain [16].

The Medical Outcome Short Form-36 (SF-36) is a questionnaire measuring an individual's QOL, regarding his or her health, as well as measuring health status. It consists of 8 subscales including physical and social function, physical and emotional limitations, health perceptions, mental health and

health transition. Additionally, a physical component summary score and a mental component summary score summarize the questionnaire. A weighted Likert scale is used for each and then summed and converted to a scale of 0-100 (negative-positive health respectively) [12]. Negative effects on quality of life, years after onset, in those who have been afflicted by Guillain-Barre Syndrome have been reported in the literature, making it important to take note of [17].

Discussion:

Guillain-Barre Syndrome is an acute, immune-mediated demyelination of the peripheral nervous system. Weakness, sensory loss, and pain manifest following the myelin damage, in addition to potential autonomic dysfunction. This presentation can lead to longer lasting issues including weakness, pain, and fatigue. Ultimately, quality of life and return to prior level of function are affected by the interactions of this sequelae, creating a challenge for physical therapists tracking progress over time in this population.

The patient's progress, measured by the QuickDASH, numerical pain rating scale (NPRS), and reported functional outcome of return to work showed great variability regarding what one would expect with recovery beyond his suspected neurological recovery. The patient's NPRS increased in pain intensity for his low back and decreased for his right shoulder. Simultaneously, his QuickDASH score showed increased disability, while his functional outcome showed increase in return to work time, though quality was affected by fatigue. Collectively, the outcome measures used do not give a clear picture of the individual's recovery. It is possible that the increase in return to work time may have influenced the other metrics, by way of fatigue. An outcome measure assessing for the level of fatigue at the same time of intake for the QuickDASH, NPRS, and functional outcome could have provided an additional point of reference to assist in the understanding of the patient's recovery. The patient's overall quality of life at each stage of rehabilitation would have provided valuable information regarding the importance of the other outcome measurements to the individual.

A study by Bernsen 2002, used a questionnaire and examination to look at the persistent impact Guillain-Barre Syndrome had on work, home, and leisure on individuals three to six years following onset. Of all the participants, 69% had minimal or no residual neurological signs or symptoms, determined in an examination of muscle power and sensory changes [2]. Despite this, the majority of the individuals reported notable change in work, leisure, and home life. They concluded that the physical demand and amount of responsibility associated with a job position was reduced in many individuals following the onset of Guillain-Barre Syndrome. Nearly half of study participants reported changes in their leisure activities. More than a quarter stated that they no longer functioned at home as well. Overall, greater than three-quarters stated that psychosocial condition had changed since the onset of Guillain-Barre Syndrome [2]. This study shows that while majority of the participants may present with improved strength and sensation, important aspects of their lives were still altered. Unplanned lifestyle changes can affect the overall quality of an individual's life and is an important aspect to be aware of.

Motor recovery has not been shown to correlate with chronic fatigue and the resultant negative effects on quality of life and daily activities [6]. Fluctuation in severity of fatigue can also make assessment difficult to determine change [4]. It has been suggested in some literature that the fatigue experienced in those who have been afflicted by Guillain-Barre Syndrome is based on one's perception of the effort required of a sustained task, rather than the actual muscle's ability to participate in that sustained task [13]. Based on the variability seen in this case report's outcome measures over time, assessment of fatigue may have provided the missing piece to make sense of the data collected.

The variability in outcomes assessed in this case study highlights the importance of defining an individuals' metric for success and recovery, especially for a condition that is known to have long-

lasting implications. Success and recovery for one patient is likely different for another. While it is important for all medical professionals, including physical therapists, to collect objective information on the progress of a patient, it is also valuable to define recovery for the individual.

Physical therapists face the challenge to improve functional capacity and health while navigating the variability prolonged fatigue and pain present in Guillain-Barre Syndrome and ones outcomes. Literature on physical therapy for Guillain-Barre Syndrome is limited in breadth and quality, leaving clinicians navigating the condition with many challenges. The variability of pain, weakness, and fatigue can greatly affect ones quality of life and can create confusion regarding progress over time, considering the objective neurological recovery often seen. Further research is needed to provide a comprehensive and meaningful outcome measurement tool or battery of measurements, embracing the intricacies of the chronic sequelae, to provide more revealing details on the recovery from Guillain-Barre syndrome in the non-acute population.

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