Curr Treat Options Neurol (2019) 21: 35
DOI 10.1007/s11940-019-0576-z

Neuromuscular Disorders (C Fournier, Section Editor)

Interprofessional Care for Neuromuscular Disease

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Published online: 1 July 2019

This article is part of the Topical Collection on *Neuromuscular Disorders*

Keywords Multidisciplinary · Interdisciplinary · Rehabilitation · Symptom management · Amyotrophic lateral sclerosis

Abstract

Purpose of review This review aims to delineate interprofessional care models for neuromuscular disease. Evidence regarding both the benefits and barriers to interprofessional neuromuscular care in both inpatient and outpatient settings is presented. Finally, opportunities to improve both access to and quality of care provided by interprofessional team clinics will be discussed.
Recent findings Although the term "multidisciplinary" is often misapplied to denote any interprofessional team-based care setting, there are important differences in team structure and dynamics in each of the three most common models: multidisciplinary, interdisciplinary, and transdisciplinary care. Evidence favors the more integrated interdisciplinary and transdisciplinary models for better patient outcomes and decreased staff burnout. Coordinated interprofessional care results in improved health outcomes, resource utilization, and patient satisfaction for persons with adult and pediatric neuromuscular disease. Distance remains the greatest barrier to specialized team-based care for this population; telehealth technologies may make interprofessional care more accessible to these persons.
Summary Despite limited evidence for the broader population of persons with neuromuscular disease, consensus guidelines increasingly support this model of care delivery. Further work may help determine effectiveness for other populations of persons with neuromuscular disease and best practices within these team-based models of care.

Introduction

Neuromuscular diseases are complex; they not only have a vast impact on mobility and function, but often give rise to secondary complications—such as pain, fatigue, and mood disturbances. An excellent example of this is ALS.

Once thought to be a disorder of "painless weakness," recent population-based surveys have demonstrated widespread non-motor secondary symptoms which are often untreated or undertreated [1••]. Due to the high levels of disability often experienced by persons with neuromuscular disease, specialty interprofessional team-based clinics have emerged as the preferred approach to providing comprehensive and efficient services to these patients.

Although the term "multidisciplinary" is often used interchangeably with "interdisciplinary," and less commonly "transdisciplinary," to refer interprofessional care approaches, there are important differences in these service delivery models (Table 1). While co-location of an interprofessional team in the same clinical area during a neuromuscular clinic meets the definition of "multidisciplinary care," interdisciplinary or transdisciplinary models, in contrast, require formal structures for communication between team members and more highly integrated care plans, and therefore may provide advantages over the multidisciplinary model in order to provide more seamless care of these complex patients. In the rehabilitation literature, the "interdisciplinary" team approach has been considered the standard of care for more than 30 years [2]. This approach is preferred in the rehabilitation setting over the multidisciplinary model due to formal team communication, which leads to decreased likelihood of conflicting recommendations or plans from the team, and decreased burden on the patient and caregiver in terms of coordinating multiple individual recommendations and follow-up plans from multiple providers.

Membership of the interprofessional team depends on the particular needs of the patient population served and may be fluid over time with changes in the therapeutic landscape. Clinical practice guidelines often outline details for personnel who are required or suggested to comprise the team. New breakthroughs in understanding the genetic or molecular basis of these diseases will likely only add to the list of professionals who would be of service to patients in the interprofessional clinic—for example, given the growing interest in genetic testing for persons with sporadic as well as familial ALS [3], genetic counselors may be a valuable addition to the interprofessional team. New disease-modifying therapies as well as increasing pharmaceutical options for symptom management for neuromuscular patients may also create demand for additional staff on the team.

Neuromuscular disease may present a unique paradigm change for the interprofessional care team due to

Table 1. Interprofessional care models

	Multidisciplinary	Interdisciplinary	Transdisciplinary
Patient evaluations	Individual discipline evaluations occur in a shared clinical space	Individual discipline evaluations occur in a shared clinical space	Co-treat or shared appointments are encouraged
Overlap between team members	No explicit overlap	No explicit overlap	"Role release," approach or sharing of discipline responsibilities by each team member or blurring of distinctions between disciplines
Team communication	Formal meetings not required	Formal meetings are required	Formal meetings are required
Treatment plan	Individual treatment plans are created by each discipline	A comprehensive coordinated treatment plan is developed	Team member assessments are integrated into a unified treatment plan
Team hierarchy	Physician is the undisputed leader of the team	Physician facilitates team as an equal member	Physician facilitates team as an equal member

the progressive trajectory that characterizes many of these disorders. Rather than focusing efforts on curative interventions and restoring lost function, the interprofessional care team for neuromuscular patients has three primary aims: prevention of secondary complications (such as pain, wounds, contracture, secondary medical comorbidities, uncontrolled symptoms), remediation of the underlying impairment when possible, and provision of compensatory strategies to enhance function. Dal Bello Haas and colleagues provide an overview and specific examples as to how this framework is applied in the setting of progressive neurodegenerative disorders, including ALS [4]. This framework may be used by each member of the interprofessional team as applied to their particular interventions and strengths.

Care settings for interprofessional teams

Inpatient care

Interprofessional care is a core tenet of acute rehabilitation, and the history of the field of rehabilitation in the USA is inextricably linked to neuromuscular disease. Early leaders in the field of Physical Medicine and Rehabilitation challenged the traditional approaches to treating inpatient polio survivors through immobilization and instead advocated for active and functional rehabilitation. Today, Medicare reimbursement guidelines include the category of "neurological disorders," which specifically includes muscular dystrophy, motor neuron disease, and polyneuropathy as one of the 13 groups of diagnoses from which 75% of admissions to acute inpatient rehabilitation facilities must pertain for a facility to maintain funding for inpatient admissions. Inpatient rehabilitation care remains common for individuals with acute neuromuscular disorders, such as Guillain-Barre syndrome. However, admissions to an inpatient rehabilitation facility for management of persons with chronic or progressive degenerative neuromuscular conditions are much less common. Barriers to admission may include inability to tolerate high-intensity therapies or poor prognosis for functional improvement.

Outpatient care

Arguably, the bulk of care for both children and adults with neuromuscular disease occurs on an outpatient basis, with a goal of proactive, preventative, and longitudinal care. Pediatric neuromuscular care requires holistic, team-based evaluations and treatment interventions in order to meet the dynamic care needs of a child. Consensus guidelines for the management of persons with spinal muscular atrophy published in 2007 recommend interprofessional care management, although this is not clearly differentiated from referral to multiple individual specialties [5]. Updated 2018 Duchenne muscular dystrophy care guidelines provide a robust example of well-defined roles and expectations for the interprofessional care team and underscore the importance of longitudinal interprofessional care across the lifespan [6••]. The scope of care for these individuals is extending into transitional and adult neuromuscular clinics, thanks to improved survival for children with pediatric neuromuscular disease. As these transitions of care become more commonplace, the demand for similarly coordinated interprofessional care in the adult setting will continue to grow.

Many clinical practice guidelines for adults with neuromuscular disease extrapolate from the literature on effectiveness of interprofessional care in ALS as the basis for their recommendations. Clinical practice guidelines for ALS

published by the American Academy of Neurology (AAN) in 2009 specifically recommended multidisciplinary care on the basis of the available evidence suggesting better outcomes with this approach [7]. More recently, jointly published guidelines from the AAN and American Academy of Neuromuscular and Electrodiagnostic Medicine (AANEM) refer to the evidence base regarding interprofessional care of persons with ALS as the foundation for similar recommendations for clinical management of limb-girdle and distal dystrophies [8]. The European Federation of Neurological Societies (EFNS) likewise published consensus guidelines for management of chronic inflammatory demyelinating polyneuropathies which include referral to multidisciplinary care as a core recommendation [9]. In contrast, other recent guidelines for multi-system neuromuscular disorders, such as those for myotonic dystrophy type 1, omit specific recommendations on interprofessional care delivery models [10].

Evidence for interprofessional care

Benefits to the patient

Despite neurological disorders being listed as one of Medicare's 13 priority diagnoses for acute inpatient rehabilitation as discussed above, there is surprisingly limited evidence regarding the effectiveness of inpatient rehabilitation for populations with neuromuscular disease. The benefit of acute inpatient rehabilitation admissions for persons with myopathy has been described through analysis in one study of 2002–2003 data from the Uniform Data System for Medical Rehabilitation (UDSMR). This study detailed the outcomes of 951 admissions to rehabilitation for persons with primary diagnosis of myopathy and revealed an average functional independence measure (FIM) gain of 19 (out of a total of 126) points over the course of 13 days average length of stay. The calculated FIM efficiency of 1.6 (points/day) did not show a statistically significant difference as compared to adults admitted with debility (1.7) or adults with hip replacement (1.9) [11]. Another small study reported the effectiveness of inpatient rehabilitation for persons with ALS. This six-patient case series noted improvements in respiratory function (FVC) and function (ALS-FRS) associated with a 4-week inpatient rehabilitation for persons with ALS [12].

Outpatient interprofessional care for persons with ALS is associated with improved clinical outcomes as well as greater patient satisfaction. Systematic reviews report increased survival of between 7 and 11 months [13], as well as decreased frequency and duration of hospitalization stays associated with interprofessional care [14]. In addition, qualitative studies surveying patients and caregivers receiving care in interprofessional ALS clinics have found positive themes associated with the patient and caregiver experience, including greater efficiency in care provision and a sense of greater collaboration between the specialty team providing care [15]. Patients cited receiving better education about their disease process and engagement with their providers as a result of interprofessional care, and all respondents agreed that specialized interprofessional team clinics were the ideal environment for collaboration, discussion, and decision making [16].

As discussed in the introduction, one way in which care delivered by an interprofessional specialty team care may lead to decreased morbidity and mortality is through proactive patient and caregiver education and

interventions to prevent secondary complications. Lopez-Gomez and colleagues examined the benefits of an interprofessional protocol in the management of patients with ALS; they found that early interprofessional management including nutritionists reduced the likelihood of severe malnutrition, regardless of presence of dysphagia. This study also demonstrated an association between early nutritional interventions and decreased hospitalization during the study period (3 days in the intervention group vs 21 days in the control population) [17].

Benefits to staff

Burnout, which is defined as depersonalization and decreased sense of personal accomplishment, is a growing concern in the medical community—and this is even more worrisome for providers managing medically complex patients. Recent physician surveys have found increasing prevalence of burnout in all specialties from 45.5 to 54.4% between 2011 and 2014. In the 2014 survey, physiatrists reported the third highest rate of burnout among specialties; neurologists reported both high levels of burnout and dissatisfaction with work-life balance [18].

Team-based care models may be protective against burnout. Half of neurologists and 78% of clinic managers surveyed in ALSA- or MDA-certified ALS clinics described "moderate," "very significant," or "critical" overall levels of stress in a survey administered by Bromberg and colleagues in 2011. Despite the admittedly high levels of stress described by these providers, 100% of neurologists and clinic managers surveyed in this study reported experiencing satisfaction in providing care to persons with ALS. Among the stress reduction techniques cited by the participants in this study were team discussions and grieving meetings. Although this study did not include a comparison population of solo practitioners, it was extrapolated from these responses that interprofessional team care is likely protective against burnout for clinical providers [19].

Another cited benefit to staff working in interprofessional team care models is the opportunity for mentorship across disciplines and training opportunities in subspecialized care, leading to more opportunities in professional development [20]. This may be particularly true for teams functioning with a transdisciplinary model, given this practice model recognizes the importance of cross-discipline training and practice as key elements.

The impact of interprofessional team care often extends beyond the clinic walls. Specialty care teams serve as resources to provide education to the patient's local or primary care team. Cup and colleagues described a system for neuromuscular centers to provide recommendations to clinicians in community primary care clinics and found that recommendations for ongoing care were generally implemented [21].

Cost-effectiveness

The interprofessional care delivery model may not be more costly than the traditional single-discipline model of care. In a cost of illness analysis, persons with ALS receiving care in Norway completed a series of questionnaires related to cost of care and found the monthly cost of interprofessional care (1336 euros) was nearly identical to general care (1271 euros) [22]. More studies would be helpful to compare the direct and indirect costs of these service delivery models both for the healthcare team (staffing, facilities) and patient (travel, lodging).

Addition of certain members to the interprofessional team may even enhance productivity of the interprofessional clinic by streamlining encounters for other providers. An example of this was integration of a pharmacist in an ALS clinic, which resulted in decreased face-to-face time required of the clinic neurologist and nurse, thereby permitting one additional patient to be scheduled per day [23].

Although interprofessional care interventions are related to decreased healthcare utilization such as hospitalization or emergency room visits, there is a paucity of cost/benefit analysis of this care model as compared to non-coordinated models of care.

Barriers to interprofessional care

Access

While access to subspecialized care is challenging for rural-dwelling individuals in the USA, access to specialized interprofessional care teams can be even more scarce. A recent study found nearly half of all persons with ALS live > 50 miles from a multidisciplinary center, and 25% lived > 100 miles from the centers [24•]. Indeed, in one qualitative survey to persons with ALS, the top disadvantage of attending a multidisciplinary clinic was travel distance [25]. Travel distance is compounded by disability, a factor echoed in another recent qualitative study regarding patient's perspectives on multidisciplinary care in Saskatchewan, Canada [26•].

Inpatient interprofessional care through acute rehabilitation admissions may eliminate some of the barriers to accessing specialty team care; however, this is not common practice for patients with established diagnoses who are experiencing progressive disability due to their primary neuromuscular condition. Current inpatient rehabilitation metrics focus on increasing functional independence measures, which may not be the primary endpoint in this patient population. Insurers may therefore be reticent to approve these costly rehabilitation admissions.

Cost of interprofessional care

While the benefits of providing a patient-centered, streamlined care experience are many as outlined above, this model may not optimize reimbursement for care. A multi-center study of eighteen certified ALS centers in the USA found the average cost of staffing the interdisciplinary team to be $500 per person seen in the clinic; however, this figure did not account for the significant amount of generally uncompensated indirect patient care time (phone/email follow-up, patient forms/letters, consulting with other clinicians, and other activities) of approximately 4 h per staff member per week. A lack of comparison data in this study makes this difficult to compare these costs of direct and indirect care to that of a single-discipline provider clinic model [27]. Despite a very similar cost of staffing interprofessional care of $580 per patient, another study noted that insurance reimbursement covered less than half of this cost, resulting in a loss to the institution of over $300 per patient visit [28••]. In addition, insurance may fail to reimburse for therapist visits within the specialty clinic when the patient is already engaged in therapies in the home or in the outpatient setting outside the interprofessional setting. While nonprofit organizations may subsidize or

offset the costs of care in these specialty clinics, depending on charity organizations to facilitate what is considered the standard of care is not optimal and certainly does not provide incentive to promote growth of this service delivery model.

Opportunities to enhance interprofessional care

Patient and caregiver suggestions for improvements

Apart from distance and cost of care, patient and caregiver surveys have identified ways in which the care experience may be improved in the interprofessional team clinic. Long, rigid clinic formats and delays between provider appointments are described as fatiguing for persons with neuromuscular disease [25]. In addition, there is growing recognition that the caregiver's well-being should also be addressed during the routine patient visit [26•]. Caregivers of persons with neuromuscular disease may experience challenges related to physical and emotional well-being, as well as distress related to the financial impact of loss of family income from work [29] or financial strain of expenses of medical care, durable medical equipment, and home modifications as caregiving needs increase [30].

Technology to enhance access to care

As geographic inaccessibility remains one of the leading barriers for persons with neuromuscular disease to access interprofessional care, clinical video telehealth is a means to extend support and expertise to both rural healthcare teams and patients.

Interprofessional team consultations have been delivered by telehealth to remote providers—both within the USA and abroad. In one, a US-based team provided routine live consultations to a remote team in the United Arab Emirates, during which recommendations on diagnostic workup and management were provided [31]. Another described remote interprofessional telehealth team consultations involving teams based at a tertiary medical center to rural regions within the USA as well as distant territories [32]. Both examples used the approach of involving teams at both ends to facilitate communication in real time to ensure the information exchange was accurate and complete, as well as promote collaborations in care and provide educational opportunities to non-specialized providers.

While sporadic interprofessional consultations are helpful to mentor a non-specialized team, telehealth can also serve a unique role for follow-up care for established neuromuscular patients. This model is particularly appealing to facilitate access to care for persons who experience progressive disability as their disease progresses. Surveys of neuromuscular patients reveal high levels of interest in telehealth follow-up care, particularly among those patients with physical disabilities or geographical barriers (travel > 1 h) [33].

Outcomes of telehealth interventions for persons with ALS have been reported and reveal benefits for patient satisfaction, cost, and health outcomes. High levels of patient acceptance and satisfaction with telehealth services have been reported [34, 35]. Telehealth monitoring of non-invasive ventilatory support has been associated with decreased emergency room visits and hospital admissions [36]. A systematic review analyzed 16 studies of telehealth

interventions for ALS, concluding that survival was equivalent for persons with ALS receiving care by telehealth as compared to those receiving in-person care in clinic [37].

Conclusion

Multidisciplinary care describes only one of three interprofessional health care delivery models for management of patients with neuromuscular disorders. Interprofessional care is associated with improved outcomes for patients as well as improved team dynamics and decreased stress or burnout for staff. The greatest amount of literature and guidelines on this subject relates to ALS care in adults and Duchenne muscular dystrophy in the pediatric population; these frameworks may provide useful models to address broader neuromuscular disease conditions. While most literature favors improved outcomes with coordinated interprofessional care, challenges exist related to poor accessibility for patients due to distance and disability, poor reimbursement for coordinated care models, and poor tolerance of extended clinic visits related to patient's fatigue. Opportunities exist to provide consideration to interventions that would better support caregivers as well as patients with neuromuscular disease. Telehealth interventions provide promising means to ameliorate barriers related to access and fatigue. Further research would be beneficial to validate the most effective model of interprofessional care.

Compliance with Ethical Standards

Conflict of Interest
The authors declare that they have no conflicts of interest.

Human and Animal Rights and Informed Consent
This article does not contain any studies with human or animal subjects performed by any of the authors.

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