Camp-based research in neuromuscular disorders: A novel framework for natural history data collection

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ABSTRACT

Neuromuscular camps–dedicated retreats for individuals with conditions such as Duchenne Muscular Dystrophy and Charcot-Marie-Tooth disease–represent a profoundly underutilised resource for rare disease research. These camps provide unparalleled access to authentic, lived experiences that are rarely captured in clinical or support group settings. Within this environment, challenges surrounding mobility, personal care, socialisation, and energy budgeting are navigated organically, offering a holistic view of adaptation and resilience. Integrating prospective research methodologies, such as unobtrusive observational studies, wearable technology, and gamified assessments, into the camp setting could yield rich, real-world data without compromising the core purpose: joy, connection, and empowerment. This paper argues that neuromuscular camps, if approached ethically and collaboratively, can serve as natural history platforms, shaping future research and interventions while preserving the essential spirit of these transformative experiences. This paper proposes a hybrid model that integrates research methods such as wearable technology, narrative tools, and gamified assessments into camp life without compromising the primary ethos of joy and empowerment. Neuromuscular camps, if approached collaboratively and sensitively, can meaningfully reshape how we collect and interpret data in neuromuscular disease research.

Keywords: Paediatric Neurology; Wearable Electronic Devices; Muscular Dystrophy; Charcot-Marie Tooth Disease

1. Introduction

Muscular dystrophies and related neuromuscular disorders are life-altering, progressive diseases that impose significant burdens on patients and caregivers. Though these diseases are well-characterised clinically, the translation of these findings into real-world functional impact remains limited. Natural histories are essential for quantifying disability and functional impact of muscular dystrophies, with these factors intrinsically linked to quality of life, yet traditional clinic-based assessments often fail to capture the nuanced realities of daily living.[1] By contrast, neuromuscular camps offer an opportunity to immerse clinicians and researchers in authentic environments where adaptation, identity, and community unfold naturally. Understanding the impact of functional minutiae on quality of life is tantamount to ensuring comfort and prioritising tailored, patient-centred care. This reflection, grounded in firsthand experience at a neuromuscular camp, explores how such settings can inform both clinical care and research, provided that research integration remains secondary to the camp's primary mission of fostering joy and connection. Moreover, while this reflection pivots around the neuromuscular camp I attended, these tenets could readily apply to camps where individuals with rare or uncommon diseases are brought together, with other such examples being Type 1 diabetes, paediatric cancers, and intellectual disabilities.[2,3,4]

1.1 Limitations of Clinical Assessments

Clinical histories are inherently constrained by recall bias, time limitations, and the artificiality of the healthcare environment as opposed to real-world conditions. Clinic-based assessments often focus on the high-yield aspects of a patient's condition but overlook the subtleties of activities of daily living (ADLs)–from toileting to social engagement–that define patient experience. Neuromuscular camps, through their non-clinical atmosphere, allow for unobstructed observation of adaptation, fatigue management, and social development.

1.2 The Camp Environment

Contextually, neuromuscular camps are low-pressure, non-clinical environments comprised of a group of children with various neuromuscular disorders. For example, the camp I attended included 10 children aged 10-17, staffed primarily by one healthcare professional for general support. Other camps at national and local levels vary widely: some serve larger groups (up to 100 campers) and employ multidisciplinary teams including doctors, nurses, respiratory therapists, and other allied health professionals. Despite these differences, all camps share a common goal: to offer children living with neuromuscular disorders an opportunity to participate in a summer camp experience that is safe, inclusive, and distinct from traditional camps, with a focus on recreation, peer connection, and empowerment.

1.3 Ethical Considerations

Recognising that campers attend neuromuscular camps primarily to enjoy a break from medicalised environments, any research projects must prioritise camper autonomy, informed consent, and the preservation of the camp's core spirit. Thus, research methods should avoid direct demands on campers during camp weeks: no surveys, testing, or formal assessments should be administered

during the camp itself. Minimally intrusive approaches–such as observational data collected by dedicated research personnel, pre- and post-camp surveys, and wearable technologies–may be feasible while respecting camper autonomy. Research activities must remain adjunctive and secondary to the camp's primary mission of fostering joy, connection, and empowerment.

All reflections included within this piece are anonymised, with no data collected beyond general observation.

2. Key Themes Emergent from Camp Life

2.1 Mobility and Adaptation

Campers display a spectrum of mobility, with adaptive strategies emerging organically, whether through creative participation in activities, modified self-care routines, or collaborative problem-solving. These adaptations, often invisible in clinical settings, highlight the fluidity of functional ability and the ingenuity of young people living with chronic disease.

For example, a group 'chair yoga' subtly challenged campers to adapt to the circumstances, given the challenging nature of many of the exercises. Many improvised, whether through reduced amplitude of movement or more accessible exercises, though others refrained from participating due to perceived inability to engage properly or a lack of confidence. Other common adaptations included rolling over for hoisting or washing, straws for drinking, or shuffling for changing.

Maturity was exercised by all campers in their capacity to recognise their limits and ask for help when required.

2.2 Sleep, Fatigue, and Energy

Fatigue and sleep disturbances are pervasive yet poorly quantified in neuromuscular disorders. Clinical fatigue questionnaires, such as the Fatigue Assessment Scale (FAS) or CIS-8, are non-specific and lack comprehensiveness. Fatigue questionnaires are poorly validated in children, which is further compounded by the paediatric fatigue questionnaire lacking specificity, also.[5]

For neuromuscular disorders, the process of energy budgeting involves strategically spending or conserving energy and activity based on context.[6] Energy budgeting requires a high level of self-regulation, revealing adaptive mechanisms and patterns of fatigue that may elude standard cross-sectional questionnaires.

Future research in this domain should target the development of standardised metrics for quantifying fatigue in neuromuscular disorders, in addition to generating longitudinal data to determine the long-term implications of energy budgeting.

2.3 Friendship, Identity, and Autonomy

The camp setting invited these children with such high functional needs to undergo psychosocial development, foster their autonomy and develop peer connections.

Among campers, camaraderie was observed through the shared experience of living with a chronic disease, fostering a sense of community. Mentorship was also developed, with older campers and guest speakers guiding younger peers through the complexities of living with a rare disease. These psychosocial dimensions are critical yet underrepresented in clinical research.

2.4 Assistance from Support Staff and Camp Volunteers

The presence of multidisciplinary staff–carers, a psychologist, a nurse–facilitates holistic support and offers clinicians invaluable, immersive learning opportunities. Embedding clinicians into these environments, even as silent observers, can profoundly inform patient-centred care and professional development. Prospective approaches for incentivising clinicians to participate beyond volunteering could include continuing professional development (CPD) points or points towards training programs or fellowships.

3. Clinical and Research Implications

Any research embedded into camp settings must be adjunctive, non-intrusive, and co-designed with campers and families to ensure both ethical integrity and participant engagement. Informed consent, autonomy, and the preservation of camp ethos are paramount; research modalities should never supersede the camp's primary purpose of fostering joy, connection, and empowerment.

3.1 Functional Observations

Integrating direct and indirect observational assessments has proven highly effective in clinical environments, with strong translatability to neuromuscular camps.[7]

For example, direct observational protocols–where trained clinicians or researchers systematically log real-time behaviours, adaptations, and social interactions–have been successfully implemented in rare disease registries and paediatric rehabilitation programs to capture authentic, context-dependent data.[8] Indirect feedback could also be elicited from carers or camp staff, collected at specific intervals using standardised or digital applications. This method would mirror successful models in autism spectrum disorder (ASD) camps and inclusive educational settings, where multi-informant perspectives enhance the reliability of qualitative data.[9] Synthesising real-world observations into natural history datasets can inform future interventions and policy in neuromuscular disease research.[10]

3.2 Wearables and Technology

Wearable technology has been transformative in chronic disease management and paediatric preventative health, offering a feasible and evidence-based research method that could be easily applied to camp settings.[11,12]

Table 1: Non-Invasive Methods for Integrating Research into Camps

Method	Benefits	Drawbacks
Functional Observations	Captures natural behaviours; low disruption.	Potential recall bias; subjectivity.
Wearables	Real-time monitoring of movement, fatigue, sleep, and other metrics.	Comfort, adherence; data interpretation.
Surveys	Objective, real-time data, naturalistic context.	Response rates; potential for response bias; survey fatigue.
Gamification	Higher engagement, accuracy, motivation.	May alter test validity; competition may exclude some.
Digital Storytelling	Rich qualitative insights, empowerment.	Self-disclosure concerns.
Buddy Interviews	Peer-to-peer format yields authenticity, increased disclosure.	Recording conversations may impact authenticity.
Camp Hackathon	Innovation and creativity, highlights key challenges..	Logistical complexity; feasibility of implementing solutions.
Adaptive Tech	Provides user feedback to inform future designs.	Access to equipment; potential for discomfort.

Wrist-worn accelerometers have previously been successfully integrated into Duchenne populations, while smart insoles have implications for researching the biomechanics of movement in other neurological conditions.[13,14] These wearable technologies could provide granular data on metrics such as ambulation, sleep patterns, and activity levels.

Studies in cystic fibrosis and chronic obstructive pulmonary disease have also incorporated microparticulate sensors to explore correlations between environmental factors and symptoms, which could be translated to humidity and fatigue in neuromuscular disorders.[15]

3.3 Survey Tools

While surveys might appear less aligned with the immersive ethos of the camp, their strategic application can yield critical quantitative and qualitative data. Short, targeted surveys administered at key time points have been successfully integrated into paediatric camps, capturing changes in mood and social connectedness.[16] Prospective surveys could also be implemented to enhance the dataset to track long-term adaptation, functional decline, and the sustained impact of camp experiences on quality of life, creating a more enriched, longitudinal dataset.

Ecological momentary assessment (EMA) techniques could also be incorporated to capture real-time perceived exertion levels during specific camp activities. EMA has previously been validated in studies on chronic pain and can provide valuable insights into the dynamic interplay between fatigue and activity in paediatric neuromuscular disorders.[17]

3.4 Gamification

While gamification has demonstrated promise in clinical and educational settings, its integration into camp activities must be approached cautiously to avoid detracting from the camp's core recreational purpose.[18] Any such interventions would need to be entirely optional, minimally intrusive, and designed collaboratively with campers, families, and staff to ensure that the camp does not become medicalised. Potential applications might include optional, light-hearted activities outside core camp hours, such as team challenges or energy budgeting games, which could offer observational insights into functional capacity and fatigue management without imposing on campers' autonomy or enjoyment.

3.5 Narrative Data Collection

Camp-based narrative methods—like digital storytelling and buddy interviews—offer complementary, low-disruption ways to document lived experience. These approaches, drawn from disability advocacy and peer-support literature, can yield emotionally authentic, ethically sound qualitative data.[19,20]

3.6 Adaptive Tech and Hackathon

Trialling assistive technologies and adaptive equipment playfully in camp settings provides a unique opportunity

to gather real-world feedback and inform future device employment. Mobility aids, exosuits, and adaptive gaming interfaces are increasingly integrated into clinical settings, and their deployment at neuromuscular camps can provide campers with opportunities to explore their utility and usability in a supportive environment.

Similarly, a camp hackathon would provide campers with a platform to articulate what affects them most regarding their condition by designing their 'dream tool' or assistive device to improve daily life. This represents an innovative approach to fostering creativity and generating user-centred solutions. Taking this a step further, it would be even more insightful for the campers to showcase their designs to a panel of experts (e.g. engineers, therapists, designers) who could provide constructive feedback and consensually submit the most innovative ideas to technological companies for future research.

3.7 Hypothetical Pilot Study

I propose a multi-site, two-year longitudinal study encompassing all major neuromuscular camps in a specific country or region. The study would integrate wearable accelerometry, ecological momentary assessments (EMA), and structured observational logging to capture daily lived experience in context. Ten core domains—mobility, fatigue, mood, sleep quality, energy budgeting, social engagement, pain, independence, affective tone, and adaptive function—would be tracked non-invasively. Data collection would be embedded into routine camp life, with protocols co-designed alongside caregivers, staff, and youth participants to ensure minimal disruption and maximal relevance. Continuous feedback loops would inform iterative adaptation across study arms.

4. Conclusion

Neuromuscular camps offer a unique, immersive window into the lived realities of rare disease, capturing dimensions of function, adaptation, and psychosocial growth that are inaccessible in clinical settings. When research is integrated ethically and collaboratively, with strict prioritisation of camper autonomy and joy, these camps have the potential to serve as invaluable platforms for natural history data collection and patient-centred innovation. The challenge and opportunity, however, lie in harnessing this potential without compromising the transformative, joyful essence of the camp experience. This paper advocates for carefully designed, minimally intrusive research approaches, co-created with campers, families, and staff, that preserve the spirit of camp while advancing understanding and care in neuromuscular disease. Through such partnerships, camps and researchers can contribute meaningfully to improving the lives of those affected by rare neuromuscular disorders.

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