

Table 2
Notable Caregiver Quotes

Theme	Quote
Care Delivery	
Convenience	"Because of the many medical complications that my daughter has, being able to have those clinic moments where we can see multiple doctors at the same time is easier for us."
Care Coordination	"The doctors can be here together, working with each other, and discussing her situation, and can come up with better ideas to how to treat her and make her life easier."
Overwhelming	"I'm going to be honest, it's stressful. There's a lot going on back to back. He doesn't like lying on the table or seeing the doctors."
Environment	"A lot of these kids may, like my son, have a G-tube. We need something to hang it on the wall, like a pole or something here so we are able to accommodate his needs here. Still being able to feed him, keep him comfortable here as well."
Communication	
Care Mapping	"I just took in a lot of great information about his present and what might be coming up in his future, which feels like a helpful map."
Shared Discussion	"It's been super helpful to have just the organization of the doctors and staff to help with appointments and communicate with each other and make the next steps super clear for me. What I need to do at home and what next appointments I have coming up."
Care Quality	
Comprehensive Care	"Just meeting all of these disciplines today. The dental, we talked about dental hygiene. The orthopedic surgeon gave us exercises to help him increase his ability to stand. The dietician, was on the money, she got him to agree to eating a new food."
Compassionate Care	"The doctors spend time with him, they were really gentle with him. They noticed that he might have been a bit nervous."
Family-Centeredness	
Caregiver Education	"Even if we don't need a doctor, they send them in and educate me on things that I didn't realize could be a potential problem. The neurologist today educated me about seizures, which it's kind of good to hear that stuff reinforced."
Empowerment	"You guys have given me the tools and I'm making sure I'm using them!"
Hope	"Being able to have this clinic is also a way for us to have hope."

of their child's care with multiple specialists to paint a complete picture of their child's health and health needs. Multiple caregivers specifically noted that the ability to see dental providers, nutritionists, and feeding specialists was a unique and integral part of their clinic experience. Lastly, caregivers acknowledged the importance of providing compassionate care to children who may not always experience it in the health care system.

3.4. Family-centeredness

Family-Centeredness referred to an emphasis on caregiver education, empowerment, affirmation, and reinforcement. Caregivers expressed appreciation for education about current and future health care concerns, as well as learning more about resources. One caregiver conveyed, "They educate me on things, such as seizures, that I didn't realize could be a potential problem," while another caregiver affirmed, "I have learned a lot here!" In addition to education, caregivers expressed that with the help of the clinic, they felt empowered to care for and make decisions

about their child. Caregivers also welcomed opportunities for both reinforcement and affirmation that "we have been doing some of the right things." Overall, they greatly emphasized the respect given to them as caregivers, as well as the family-centered nature of the clinic.

3.5. Distribution of themes

A heatmap (Fig. 3) compared the frequency of caregivers who mentioned each sub-theme with how positive or negative those comments were, based on research team consensus. For example, the theme of Convenience was mentioned by 80% of caregivers, and 100% of these caregiver comments were positive. Themes such as Comprehensive Care and Shared Discussion also had 100% positivity but were mentioned by fewer caregivers (36%). More neutral comments included those about follow-up and pre-visit preparation, which had 50% positivity and were mentioned by 32% and 18% of caregivers, respectively. Conversely, more negative comments were focused on the potentially overwhelming clinic environment. While

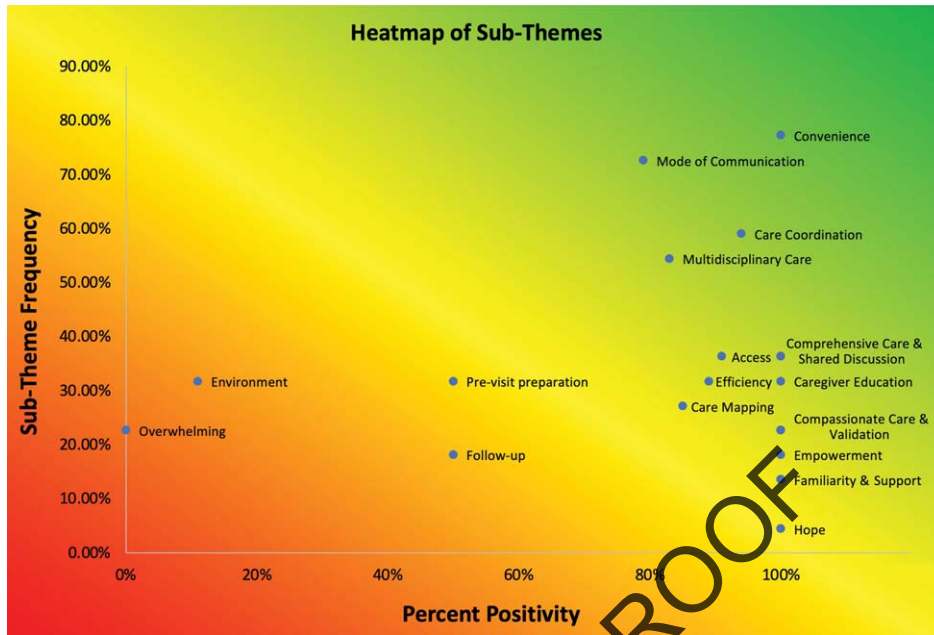


Fig. 3. **Heatmap of Sub-Themes.** Percent positivity (x-axis) denotes the percent of comments about each sub-theme that were positive. Frequency of mention (y-axis) indicates the frequency of caregivers who mentioned each sub-theme.

only 25–35% of caregivers mentioned the environment or overwhelming feelings, most comments were not positive.

4. Discussion

This is the first study to qualitatively examine perspectives of caregivers for children in a multidisciplinary neuromuscular care clinic. Four main themes emerged from these interviews: Care Delivery, Communication, Care Quality, and Family-Centeredness. Caregivers emphasized that the unique format of the clinic promoted access to care, shared care planning, and caregiver empowerment. This study demonstrated that caregivers believed the MDC model was both efficient and convenient for caregivers and patients with neuromuscular disorders. Ultimately, this study suggested that multidisciplinary team models have great potential to streamline medical care, ease caregiver burden, and promote teamwork among providers who care for children with complex medical needs.

Previous MDCs have focused on care coordination; however, their target populations, locations, and structures varied substantially [12–14, 20–22]. Moreover, few studies have utilized caregiver and patient

satisfaction as an outcome. In this study, themes Care Delivery and Care Quality clearly identified the need for convenient multidisciplinary care. Many caregivers specifically mentioned the availability of a wide variety of specialists, including those not seen at typical pediatrics clinics such as dentistry and nutrition. Not only did this allow for convenience in one visit, but caregivers expressed that this provided a comprehensive, whole-person approach to their child's care. In a previous study by Chang et al., dissatisfaction was expressed due to perceived poor care coordination and lack of integrated care across teams of providers [23]. These points highlight why multidisciplinary care is especially important for CMC, as the focus on specific conditions can lead to neglect of the patient as a whole.

Further, convenience is largely associated with satisfaction. Previous literature has shown that both convenience and office environmental factors influence patient and caregiver perspectives when they critique healthcare settings [24–26]. In a similar manner, Allshouse et al. articulated that many primary care settings are unable to meet the clinical needs of CMC alone [16]. In this study, convenience was clearly a highly desirable trait and ultimately associated with patient and family satisfaction. By establishing access to multiple disciplines

in one location, some of the burden can be taken away from caregivers when transporting patients and scheduling appointments for CMC. For example, transportation of CMC can be especially challenging in this setting due to significant functional limitations and high costs of specialized transportation in a large metropolitan area. Given that there are prior associations between low socioeconomic status and increased risk of various neuromuscular disorders, such as cerebral palsy, the financial burden of transportation on these caregivers becomes even more significant [7, 27–29]. Importantly, caregivers felt that the clinic format enhanced care coordination and teamwork among providers, allowing for more concise and efficient visits.

Communication also emerged as a frequently mentioned theme among caregivers. They described the inclusion of online communication and post-visit summaries as effective forms of information transmission. Similar concepts have been noted in previous reports in which patients have rated physicians higher online if they perceived them to have good communication skills [30]. For example, Butler et al. showed that pediatric surgeons who communicated effectively were more likely to receive higher online ratings and more positive comments [24]. All caregivers in this study felt that providers communicated the next steps in their child's care, which ultimately makes caregivers more comfortable with their children's providers.

The cumulative themes discussed by caregivers were largely positive in this study. The themes mentioned most frequently were convenience, mode of communication, care coordination, and multidisciplinary care (Fig. 3). Conversely, the environment of the clinic and its potential to be overwhelming fell towards the negative side. This is consistent with the current literature, which emphasizes that health care visits can be stressful and overwhelming for both CMC and their caregivers [16, 23, 31, 32]. While only 25–35% of caregivers in this study mentioned the environment or overwhelming feelings, the majority of these comments were negative. This can inform program leadership on pertinent areas that can improve the MDC experience. For example, providing basic refreshments, such as water and snacks, during these long visits would help families feel more comfortable. Pre-visit preparation and schedules given to caregivers can also help to alleviate some of the overwhelming feelings that they experience in the clinic when seeing multiple providers. Ultimately, increased communication between vis-

its can also help prevent stressful experiences in the clinic.

5. Limitations

Of note, the population in this study was limited to patients in an urban tertiary academic center, and this model may not be applicable to other contexts. While this study focused on the nuances of children with neuromuscular disorders, these issues overlap with many faced by CMC and their families. Lastly, as this study included only English- and Spanish-speaking patients, future studies can be expanded to include other languages.

In the future, this model has the potential to be standardized and more widely applied to children with various chronic medical conditions. This study suggests that families perceive MDCs to be effective at improving outpatient care coordination and communication for children with neuromuscular disorders as they consolidate appointments and providers into a single clinic day. There is also potential for future studies to assess clinical outcomes of patients enrolled in the NMCC, such as rates of hospitalization, length of hospital stays, and emergency department use. Cost analysis and financial outcomes can be utilized in the future to evaluate how this novel model impacts hospital systems.

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Conflict of interest

The authors have no conflicts of interest to report.

Ethical considerations

Institutional Review Board approval was received from the Icahn School of Medicine at Mount Sinai, and informed consent was obtained from all participants.

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