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Educational workshop for caregivers of children with spinal muscular atrophy: A mixed-methods study

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ABSTRACT

Introduction. Spinal muscular atrophy (SMA) is a genetic neuromuscular disorder that places a heavy physical, emotional, and social burden on caregivers. Structured therapeutic education is a key strategy for strengthening their role in daily support and care, although there is little local evidence regarding its impact.

Population and methods. Descriptive observational study with a mixed-methods approach. Four sessions of interdisciplinary educational workshops were held between 2024 and 2025 at a high-complexity university hospital in the Autonomous City of Buenos Aires. Sociodemographic variables were collected via a registration form, and satisfaction was assessed using a Likert scale (1-5) and open-ended questions, which were analyzed using inductive thematic coding.

Results. A total of 49 caregivers participated; 75.5% were women, and 79.6% were engaged in paid work. The majority were not affiliated with the institution (79.6%). The satisfaction survey was completed by 14 participants (28.6%), who gave high scores across all dimensions (averages ranging from 4.71 to 5.00). The qualitative analysis identified three key themes: peer exchange, technical empowerment, and appreciation of the professional team. Participants highlighted the need for a longer workshop and content on emerging therapies.

Conclusion. Interdisciplinary educational workshops proved to be a feasible, well-received intervention that had a positive impact on the acquisition of practical skills, emotional support, and peer interaction. Their implementation could be useful in the comprehensive care of patients with neuromuscular diseases and other complex chronic conditions in pediatrics.

Keywords: *spinal muscular atrophy; caregivers; health education; professional-family relationships; neuromuscular diseases.*

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INTRODUCTION

Spinal muscular atrophy (SMA) is a genetic neuromuscular disorder characterized by progressive degeneration of motor neurons, with motor and respiratory involvement of varying severity.[1] Although disease-modifying therapies have transformed its natural history, treatment continues to require a comprehensive and interdisciplinary approach, with families playing a central role in daily care.[1,2]

Caregivers take on complex tasks that involve a heavy physical, emotional, and social burden, with unmet needs for information, support, and care coordination.[2,3] In this context, the family-centered care model has been shown to improve the quality of care and adherence.[4,5]

Therapeutic education, understood as a structured process of training and support for disease management, is a key tool in complex chronic diseases, with evidence of improvements in knowledge and self-care skills.[6,7] In neuromuscular diseases, ongoing training is essential, as isolated interventions may be insufficient.[8,9] Furthermore, interdisciplinary group approaches promote learning, peer support, and self-care.[9,10]

Given the complexity of SMA treatment and the heavy burden placed on caregivers, it is essential to implement structured therapeutic education strategies. However, there is little local evidence regarding the impact of these interventions. The main objective of this study was to evaluate the experience of an interdisciplinary program of educational workshops aimed at caregivers of children with SMA. Additionally, the study sought to describe the sociodemographic profile of the participants and analyze the perceived usefulness of the practical tools provided for home care.

POPULATION AND METHODS

Scope and time period

The program was designed and implemented by an interdisciplinary team from the Pediatric Neuromuscular Diseases Unit at the Hospital Italiano de Buenos Aires, composed of specialists in pediatrics, pediatric neurology, motor and respiratory physical therapy, occupational therapy, psychology, neuroorthopedics, and sleep-related breathing disorders. The educational approach focused on the practical training of caregivers through participatory strategies and experiential learning. It took place at the simulation center of the Universidad Hospital Italiano in Buenos Aires, ensuring a safe training environment.

The first session was held on a Tuesday; subsequent sessions were moved to Saturdays to make it easier for families to attend. The general structure of the day is presented in *Table 1*. Each session took place between 8:30 a.m. and 3:00 p.m.

Following an initial icebreaker and group-building activity, the participants attended a joint workshop on General Care. Afterward, the caregivers were divided into four 45-minute rotating stations: Respiratory care, Self-care and daily living; Motor skills and orthopedics; and Reflection. Efforts were made to ensure that members of the same caregiving pair participated in different groups to encourage individual opportunities for expression and learning.

The schedule included breaks for breakfast and lunch, designed to encourage informal interaction among participants. *Table 1* provides a schematic overview, as some content and the organization of groups and stations were adapted based on the needs and number of attendees at each session.

Design

An observational, descriptive study with a mixed-methods approach, based on self-administered satisfaction surveys.

Population

Family caregivers of children and adolescents with SMA who participated in at least one session of the workshop. The analysis included those who completed the institutional form and, for the satisfaction analysis, those who responded to the follow-up survey. Duplicate records and those without implied consent were excluded.

Variables

Quantitative and qualitative variables were analyzed. The quantitative variables included a Likert scale (1-5) assessment of various dimensions of the workshop experience, such as usefulness, support, peer interaction, relevance of the content, applicability of the practical tools, and evaluation of the interdisciplinary approach. The main result was the overall perception of the workshop's usefulness, measured using a Likert scale (1-5).

The qualitative variables included the perceived benefits, the most highly valued aspects, and the suggestions for improvement reported by the participants.

In addition, the registration form was used to collect sociodemographic data on the caregivers:

Table 1. Structures of the session. Training schedule and learning strategies

Activity	Primary objective	Teaching strategy Key personnel	Opening and integration
Opening and integration *Duration: 30'*	Promote group cohesion and mutual recognition.	Recreational icebreaker activities Pediatrics team	Starting with icebreaker games using balls to identify names, ages, and types of muscular dystrophy. Use of icebreaker phrases about living with muscular dystrophy and humor-based activities: "What's a must-have in an AME parent's toolkit?" to foster a climate of trust and high emotional engagement.
Healthcare workshop *Duration: 60'*	Address health from a holistic, life-cycle perspective.	Problem-based learning Pediatrics and Neurology .	Discussion on key aspects of the life course of people with SMA, such as sexuality, the transition to adult health care, schooling, and social inclusion. The study also examined the impact of the disease on family dynamics—particularly on siblings—the responsible use of social media, and current vaccination recommendations.
Respiratory station (rotating) *Duration: 45'*	Provide training in ventilatory support and bronchial hygiene therapies	Clinical and technical simulation. Respiratory kinesiology and Sleep medicine	Implementation of the "traffic light game" for home triage: green (stable), yellow (alert), and red (emergency). Guided practice with teams of IMV and cough assist, which allowed caregivers to experience the pressures and maneuvers involved in manual cough assistance to understand the "how" and "why" of each intervention.
Self-care and daily living station (rotating) *Duration: 45'*	Optimize the caregiver's autonomy and ergonomics	Hands-on workshops and simulations. Occupational therapy, Motor skills station, Motor kinesiology, and Psychology	Analysis of real-life cases involving independence in daily living. Role-playing exercises in which caregivers took on the role of patients to experience transitions and transfers, optimizing manual techniques and fostering empathy in daily care.
Motor and orthopedic station (rotating) *Duration: 45'*	Become familiar with orthotic equipment and positioning	Interactive exhibition. Occupational therapy, Motor kinesiology, nd Neuro-orthopedics	Exhibition of orthoses (braces, splints, standing frames). Caregivers tried on the equipment to experience its limitations firsthand. A riddle game with headbands to reinforce technical terminology and understand the functional value of each device in child development.
Reflection station (rotating) *Duration: 45'*	Address the caregiver's mental health and stress management	Coping and psychoeducation workshop. Psychology team	A space to identify one's own "path of care" and overload signal. Using positive psychology tools, we worked on recognizing personal strengths and reframing self-care as a fundamental pillar for sustaining the role of a caregiver.
Inspirational closing *Duration: 45'*	Highlight success stories and strengthen motivation	Roundtable discussion with thought leaders. Pediatrics and Neurology	Interviews with adapted sports coaches, paralympic athletes, political leaders with SMA, and a mother living with the condition. The testimonials offered a vision of the future based on autonomy, full development, and the fulfillment of motherhood and fatherhood.

Note: At the end of the event, an exclusive digital resource was presented that compiles all the topics covered, action guides, and multimedia resources. This resource was provided to each family via a QR code displayed on screen, allowing them immediate and ongoing access to the information from their mobile devices.

age, gender, geographic origin, employment status, relationship to the institution, and how they learned about the workshop.

A complete breakdown of the variables analyzed—including those from both the registration form and the satisfaction survey—is provided in the supplementary material.

Ethical considerations

Minimal-risk study, in accordance with national and international regulations. It was approved by the Ethics Committee for Research Protocols at the Hospital Italiano de Buenos Aires (protocol No. 7781 PRIISA 18379 -March 30, 2026), with a waiver of informed consent due to the use of anonymized data.

Statistical analysis

Consecutive sampling was performed, including all participants in the study period. Given the descriptive and exploratory nature of the study, no sample size calculation was performed.

Categorical variables were described using absolute and relative frequencies, while quantitative variables were expressed as means and measures of dispersion or medians, depending on their distribution.

Variables derived from Likert-type scales (1-5) were analyzed as continuous variables and reported as means and standard deviations, given their widespread use in studies of perception and satisfaction.

The analysis of the open-ended responses was conducted using inductive thematic coding. After repeatedly reading the testimonies, units of meaning were identified and grouped into three emerging categories (*Table 2*). This analysis made it possible to triangulate the high scores on the quantitative scales with the caregivers' subjective experiences. The data were processed and organized in Google Sheets (Google LLC).

RESULTS

A total of 49 caregivers were registered for the four sessions of the Caregivers' Workshop held between 2024 and 2025. All of them completed the registration form and were included in the descriptive analysis of the study population. Of these, 14 caregivers (28.6%) responded to the post-workshop satisfaction survey and were included in the analysis of perceptions of the workshop.

Population characteristics

Most of the participants were female (n = 37; 75.5%), while 12 (24.5%) were male.

In terms of geographic origin, 17 caregivers (34.7%) resided in the Autonomous City of Buenos Aires (CABA); 30 (61.2%) in the province of Buenos Aires; and 2 (4.1%) in other parts of the country (Chaco and Mendoza).

Regarding employment status, 39 caregivers (79.6%) reported having paid employment, while 10 (20.4%) were dedicated exclusively to caring for the patient.

Regarding their affiliation with the institution, 10 participants (20.4%) were patients at the Hospital Italiano de Buenos Aires, while the majority (n = 39; 79.6%) were not receiving treatment at the institution.

Regarding dissemination of the activity, the main channels of awareness were social media (n = 19; 38.8%) and recommendations from family members or acquaintances (n = 18; 36.7%), followed by communication via email (n = 9; 18.4%). Other sources (institutional websites or combinations of channels) accounted for a smaller proportion.

Satisfaction and perceptions of the workshop

The quantitative analysis of the experience, based on Likert-type scales (where 1 is the

Table 2. Qualitative analysis: Perceptions and experiences of participating caregivers

Thematic area	Definition of the category	Representative quotes
Peer exchange	Interacting with others allows us to transform individual experiences into collective ones, reducing feelings of loneliness.	"Getting to know other families and sharing our daily lives [...], thanks to you, we don't feel so lonely in this daily struggle."
Technical empowerment	A greater sense of security in daily and clinical patient care through applicable knowledge.	"In day-to-day life, many things get, overlooked extremely important details [that the workshop brought to light]."
Professional evaluation	Recognition of the team's warmth and approachability of the team as a facilitator of learning.	"The staff's willingness to help, patience, friendliness, and explanations from the professionals."

minimum score and 5 is the maximum), reflects a highly positive perception among attendees. As detailed in *Table 3*, the results show high levels of satisfaction across all evaluated dimensions, highlighting remarkable internal consistency in the perception of the workshop's quality.

Qualitative analysis

Three emerging themes were identified. The results are shown in *Table 2*.

The open-ended responses were analyzed using inductive thematic coding. After repeatedly reading the testimonies, units of meaning were identified and grouped into three emerging categories (*Table 2*). This analysis made it possible to triangulate the high scores on the quantitative scales with the caregivers' subjective experiences.

Regarding the gaps identified in the workshops, a latent demand emerged to extend the duration of the workshops and to address cutting-edge topics such as "ongoing research and gene therapies". This indicates that the workshop not only served a supportive role but also acted as a catalyst for new information needs among a population highly engaged by recent therapeutic advances.

DISCUSSION

Existing evidence positions caregivers as an essential component in the management of neuromuscular diseases (NMDs), recognizing that their training and support are part of the standard of comprehensive care.[1] However, interventions designed specifically for this population are scarce, and local experience in implementing them is virtually nonexistent. Within this framework, the present study sought to describe an initial experience with an interdisciplinary intervention aimed at caregivers of children with SMA in a Latin American context.

The results show that a program of interdisciplinary educational workshops was associated with high levels of satisfaction, the acquisition of practical tools, a positive emotional impact, and a strong appreciation for peer-to-peer exchange. These findings are consistent with the evidence supporting caregiver education as an essential component in the management of neuromuscular and rare diseases, in line with the recommendations of international treatment guidelines for SMA.[1]

Concerning the participants' profiles, most served as primary caregivers while simultaneously holding a paid job. This finding highlights a sustained dual burden that complicates the psychosocial impact, as has been described in observational studies of caregivers of patients with SMA.[2,3] In this regard, the higher turnout observed when the workshop was held on a Saturday compared to weekdays suggests that barriers to access are strongly influenced by availability, which reinforces the need to design interventions that are accessible and tailored to family dynamics.

The concentration of participants in the Autonomous City of Buenos Aires (CABA, by its Spanish acronym) and the province of Buenos Aires, coupled with the limited representation from the interior of the country, highlights potential geographic barriers to access and the existence of unmet demand in other regions, which raises the need to explore expansion strategies or alternative implementation models.

An analysis of demographic cross-tabulations suggests that the workshop reached a broader audience beyond the population typically served by the institution, with a high proportion of

Table 3. Impact and satisfaction assessment of the intervention (n = 14)

Dimension evaluated	Mean ($\bar{x}$)	Standard deviation (± SD)
Wants to repeat the workshop	5.00	0.00
Sense of being heard and supported	4.93	0.27
Interaction with other families	4.93	0.27
Impact of the special guest	4.93	0.27
Appreciation of the space for reflection	4.86	0.36
Usefulness for daily care	4.79	0.43
Relevance and appropriateness of the content	4.79	0.43
Building networks among families	4.79	0.43
Applicability of practical strategies	4.71	0.47
Appreciation of an interdisciplinary approach	4.71	0.47

caregivers who had not previously been followed up with, which reinforces its potential as a tool for engaging with the SMA patient community.

Finally, the predominance of women in the role of caregiver is consistent with what has been reported in the literature on pediatric chronic diseases, which reinforces the need to consider the gender perspective when designing interventions aimed at caregivers.[2,3,6]

Peer-to-peer exchange emerged as one of the aspects most valued by participants. This finding is consistent with previously evaluated interdisciplinary group interventions, which highlight their role in providing emotional support, validating experiences, and developing shared strategies.[9,10] Similarly, the fact that most participants learned about the workshop through social media or recommendations from other caregivers reinforces the role of informal networks and family organizations in providing support for these conditions.

Regarding the acquisition of practical skills, participants highlighted the usefulness of the content for daily care. These benefits are consistent with evidence derived primarily from other pediatric chronic diseases and populations with neurological disabilities,[5-7] suggesting that they could be extrapolated to the context of SMA. However, the need to extend the duration or delve deeper into the content—as noted by several participants—is consistent with studies indicating that a single session may be insufficient for acquiring specific skills.[9]

It is particularly noteworthy that the benefits reported in this study correspond directly to the needs identified in the literature. Brandt et al.[2] described in their systematic review that caregivers of children with SMA seek practical information on the treatment of the disease, emotional support, and opportunities to connect with other caregivers in similar situations. For their part, Evkaya Acar *et al.*[3] reported that the main unmet needs of primary caregivers included access to education on specific caregiving practices and psychological support. The fact that precisely these domains emerged as the most highly valued aspects of the workshop reinforces the relevance of the intervention's design and its ability to address real, previously documented needs. The positive emotional impact observed aligns with the family-centered care model, which is widely supported by clinical studies on chronic pediatric diseases.[4,5] The workshop's interdisciplinary approach constitutes an additional strength, consistent with the evidence supporting this type of intervention in complex and rare diseases.[10]

Taken together, these findings reinforce the value of structured educational interventions as part of comprehensive care for children with complex chronic illnesses. The results suggest that interdisciplinary educational workshops could be systematically integrated into care settings, such as day hospitals or specialized follow-up units, constituting a feasible and replicable strategy to strengthen the caregiver's role, improve the quality of home care, and promote the development of support networks.

Limitations

First, this is a single-center study, which could limit the generalizability of the findings to other contexts. Furthermore, the sample size is small, and the perception analysis was based on the subgroup of participants who voluntarily completed the survey (28.6%), which introduces a potential selection bias, with an overrepresentation of more motivated caregivers or those with higher levels of satisfaction. However, the observed response rate is consistent with that reported in similar studies on educational interventions and should be taken into account when interpreting and generalizing the results.

On the other hand, the researchers belong to the institution organizing the workshop, so the possibility of social desirability bias in the responses cannot be ruled out. However, strategies were implemented to mitigate these biases, such as the use of anonymous, self-administered surveys, as well as qualitative analysis through independent coding.

There was also no pre- and post-intervention assessment, which limits the ability to measure changes attributable to the workshop in terms of knowledge or perceptions. The descriptive and exploratory design of the study does not allow for the establishment of causal relationships but rather serves to generate hypotheses for future research.

Finally, the qualitative findings should be interpreted with the understanding that the thematic analysis was exploratory in nature and was based on a limited number of open-ended responses. The themes identified reflect emerging trends within the sample studied and serve as a starting point for future research.

CONCLUSION

Interdisciplinary educational workshops for caregivers of children with SMA are a feasible, well-received intervention that has a positive impact on perceptions of support, the acquisition of practical tools, and peer-to-peer exchange.

These findings underscore the value of incorporating therapeutic education strategies into family-centered care models, tailored to the actual needs and circumstances of caregivers.

Future studies will be needed to assess its long-term impact, its implementation in other contexts, and its incorporation into clinical practice. ■

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The supplementary material provided with this article is presented as submitted by the authors. It is available at: https://www.sap.org.ar/docs/publicaciones/archivosarg/2027/11114_AO_Squitin_Tasende_Anexo.pdf

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