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Caregivers' Perspectives on the Significance of Physiotherapy in Spinal Muscular Atrophy: A Cross-Sectional Study on Knowledge, Attitudes, and Practices

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KEYWORDS

Spinal Muscular Atrophy, Physiotherapy, Caregivers, Rehabilitation, KAP

ABSTRACT:

Background and Need:

Spinal Muscular Atrophy (SMA) is a rare neuromuscular disorder requiring long-term multidisciplinary management. Physiotherapy plays a crucial role in preserving function and preventing complications. This study aimed to evaluate the knowledge, attitudes, and practices (KAP) of caregivers on significance of Physiotherapy in SMA.

Material and Methods:

A cross-sectional survey was conducted with 30 caregivers of the children aged between two to twenty-one years and diagnosed with SMA Types II and III across Maharashtra. A structured KAP questionnaire was generated and validated in English, Hindi, and Marathi. Data were collected through face to face interviews and data were analysed. Descriptive statistics including frequencies, percentages, and mean (SD) were used to report the findings.

Results:

Most caregivers (83.3%) were aware of SMA and (86.7%) identified its genetic basis. Physiotherapy was recognized as essential intervention by (93.3%), though few (26.7%) reported limited access to reliable information and evidence. All children received Physiotherapy, mainly home-based (73.3%). Financial constraints (83.3%), lack of nearby centers (63.3%), and transport issues (60%) were key barriers to receive the Physiotherapy care. Despite challenges, caregivers acknowledged Physiotherapy's role in improving function (70%) and quality of life (63.3%). The caregivers desired support for financial aid (70%) and multidisciplinary care access (80%).

Conclusions:

Caregivers expressed sound knowledge and a positive attitude towards Physiotherapy in SMA management. However, barriers such as high cost of care, long travel distances, and limited access to services restricted implementation of the required intervention. Caregivers do value Physiotherapy in SMA care but due to certain constrains they did not achieve the maximum benefit of Physiotherapy. Therefore, addressing these factors through empathy is essential to improve Physiotherapy care outcomes.

1. Introduction

Spinal Muscular Atrophy (SMA) is a rare, progressive genetic neuromuscular disorder that significantly impairs motor function, muscle strength, and independence in affected individuals, particularly children [1]. Mutations or deletions in the SMN1 gene reduce the availability of the survival motor neuron (SMN) protein, a key molecule needed for the upkeep of motor neurons. The resulting protein deficiency leads to the slow deterioration of motor neurons, which manifests as muscle weakness, low muscle tone, and impaired voluntary movements. The global occurrence of Spinal Muscular Atrophy is estimated to be around one case per 10,000 live births [2] Based on the age at which motor symptoms first appear and their intensity, SMA is classified clinically into four main types. Type I is the most severe form, presenting in infancy and often requiring intensive respiratory and nutritional support. Type II typically emerges between 6 and 18 months of age; affected children are able to sit independently but face difficulty standing and walking, and may develop scoliosis or respiratory complications. Type III, also known as Kugelberg-Welander disease, has a later onset after 18 months and is marked by progressive proximal muscle weakness, especially in the lower limbs. These children often walk into adolescence but gradually lose ambulation. Long-term survival and motor outcomes in SMA vary substantially across types, with functional decline progressing despite compensatory adaptations children often walk into adolescence but gradually lose ambulation. Type IV is the mildest form, usually presenting in adulthood, with minimal functional limitations [1,3,4].

Physiotherapy plays a vital role in addressing the extensive caregiving demands associated with SMA by directly targeting respiratory and motor impairments [5]. Tailored physiotherapy interventions aim to strengthen muscles involved in swallowing and chewing, thereby reducing feeding difficulties and the risk of aspiration. Respiratory techniques such as assisted coughing and chest mobilization are used to optimize lung function and minimize respiratory infections. Weight-bearing activities and targeted mobility exercises play a crucial role in managing SMA by helping to maintain joint flexibility, prevent contracture development, and support sustained mobility [3]. Physiotherapy also supports postural control and functional strength, enabling children to participate in daily tasks and reducing the overall caregiving burden. Consistent and early physiotherapeutic intervention not only enhances present function but also prevents secondary complications, making it a key component in comprehensive SMA management [6].

Although gene-based therapies and supportive treatments for SMA are advancing rapidly [7,8], the long-term success of care depends significantly on active caregiver involvement, particularly in implementing physiotherapy interventions [5,9]. Physiotherapists develop therapeutic protocols, but caregivers are responsible for consistent application of these strategies in the home environment. However, caregivers vary in their level of knowledge, attitudes, and confidence regarding physiotherapy practices. Currently, there is a lack of structured evidence examining caregivers' knowledge, attitudes, and practices (KAP) specifically related to physiotherapy in children with SMA [10]. This gap presents a barrier to designing effective educational and support strategies that could enhance adherence and outcomes.

Given that physiotherapy is central to managing functional limitations across all SMA types, informed and engaged caregivers are crucial to maintaining mobility, minimizing deformities, and supporting respiratory health [5,9]. Therefore, this study aims to systematically explore caregivers' perspectives on physiotherapy by assessing their knowledge, attitudes, and practices. The findings will help identify gaps and barriers that hinder optimal Physiotherapy at home, and inform targeted interventions to empower caregivers as active partners in rehabilitation. Ultimately, this caregiver-therapist collaboration is essential for improving the quality of life of children living with SMA [11,12,13].

2. Methods

2.a Material and Methods:

This study employed a cross-sectional survey design to assess the knowledge, attitudes, and practices (KAP) of caregivers of children diagnosed with Spinal Muscular Atrophy (SMA). A total of 30 caregivers of children aged between 2 and 21 years, diagnosed with SMA Types I, II, or III, participated in the study. Ethical approval was obtained from the Institutional Ethics Committee prior to study initiation. All ethical principles were followed, including confidentiality, anonymity, and voluntary

participation. Written informed consent was obtained from all SMA caregivers as per the Helsinki guidelines after they were informed about the study objectives, procedures, benefits, and potential risks. Participants were assured of the right to withdraw at any point without any consequences.

2.b Development of the Questionnaire

A structured SMA-specific KAP questionnaire was developed to guide data collection. The development followed a three-step process to ensure validity and clarity. First, a comprehensive literature review was conducted to identify core areas relevant to SMA, physiotherapy, and caregiving practices. Questionnaire items were drafted and grouped into three domains: knowledge, attitude, and practice. Next, a multidisciplinary expert panel comprising ten professionals including neurologists, paediatricians, physiotherapists, respiratory therapists, social workers, and special educators reviewed the content for relevance and clarity using a four-point scale 1 = Not clear, 2 = Somewhat clear, 3 = Clear, 4 = Very clear). Based on expert feedback, ambiguous items were rephrased, redundant content was removed, and essential topics were incorporated.

Following validation, the questionnaire was translated into Hindi and Marathi to ensure accessibility. Back-translation to English was conducted to maintain semantic equivalence, with final approval by language experts. The questionnaire was thus made available in English, Hindi, and Marathi, supporting both digital and interviewer-administered formats.

2.c Sample Identification and Recruitment

Given the rarity of SMA estimated at approximately one in 10,000 live births a purposive sampling strategy was adopted to ensure inclusion of relevant and information rich participants. Eligible caregivers were those of children aged 2 to 21 years diagnosed with SMA Types II or III, receiving physiotherapy services through a clinical or support organization affiliated with the study. Inclusion criteria required that caregivers be proficient in one of the study languages (English, Hindi, or Marathi) and available for structured interviews. Caregivers of children with other unrelated neurological or genetic conditions were excluded.

Participant recruitment was initiated via telephone outreach using contact databases provided by clinical and advocacy organizations. Prospective participants were briefed on the study's objectives and ethical safeguards. Those who expressed interest received a participant information sheet and consent form, either in person or by email, in their preferred language. Informed consent was obtained accordingly.

2.d Data Collection Procedure

Data collection was conducted over a six-week period. The validated KAP questionnaire was administered using Google Forms. For caregivers with limited digital literacy, researchers facilitated the process by reading items aloud and offering clarification when necessary without influencing responses. Interviews were conducted either face-to-face or via audio/video calls, offering convenience and minimizing literacy-related barriers. All responses were digitally recorded and securely stored to maintain data integrity. This hybrid approach ensured high response rates and standardization of administration across participants.

3. Results

The study included 30 caregivers of children diagnosed with Spinal Muscular Atrophy (SMA), with ages ranging from 2 to 21 years. The mean age of the children was 9.1 ± 5.6 years, and the average duration since diagnosis was 5.9 ± 4.1 years. A majority of the children were male (76.7%), and most were diagnosed with SMA Type II (76.7%), while the remaining had SMA Type III (23.3%). No participants reported cases of SMA Types I or IV. The demographic and clinical characteristics of the study participants are summarized in Table 1.

Variable	Mean (SD)
Age (years)	9.1 (5.6)
Years since diagnosis	5.9 (4.1)
Gender	Male- 23, Female- 7
SMA type	SMA type I- 0 SMA type II - 23

	SMA type III- 7 SMA type IV- 0

Table 1.

3.a Knowledge

The findings revealed a substantial level of awareness regarding SMA among caregivers. A total of (83.3%) respondents demonstrated familiarity with the condition. Specifically, (76.7%) reported prior awareness of SMA, while (23.3%) had no previous knowledge. Genetic mutation was correctly identified as the primary cause of SMA by (86.7%) of participants. However, a small percentage believed SMA resulted from infections (3.3%) or childhood injuries (6.7%), and (3.3%) were uncertain about the cause. Despite high disease awareness, (26.7%) of caregivers reported difficulties in accessing reliable information. Physicians (43.3%) and the internet (26.7%) emerged as the most commonly used sources of information, whereas newspapers were the least utilized (3.3%).

In terms of treatment options, physiotherapy was the most frequently cited intervention (76.7%), followed by medication (63.3%), nutritional support (46.7%), injections (40%), and respiratory support (33.3%). Caregivers also evaluated the quality of life of children with SMA across various domains. Physical health was rated as poor by (33.3%), fair by (40%), good by (23.3%), and excellent by (3.3%). Regarding respiratory issues, (26.7%) rated them as poor, (26.7%) as fair, (40%) as good, and (6.7%) as excellent. Peer and social interactions were perceived as poor by (3.3%), fair by (43.3%), good by (50%), and excellent by (3.3%). In assessing independence in daily living, (33.3%) of caregivers rated it as poor, (30%) as fair, (33.3%) as good, and (3.3%) as excellent. Emotional and psychological well-being was rated poor by (6.7%), fair by (43.3%), good by (43.3%), and excellent by (6.7%).

3.b Attitude

The caregivers expressed a largely positive attitude toward the role of physiotherapy in SMA management. A majority (93.3%) believed that physiotherapy is essential for improving the functional abilities of children with SMA, whereas only (6.7%) disagreed. Regarding the time and effort required for physiotherapy, (66.7%) of caregivers stated that it was worthwhile, (30%) were neutral, (10%) found it somewhat worthwhile, and (3.3%) considered it not worthwhile.

In terms of caregiving challenges, the most frequently cited issue was the high cost of medical treatment (83.3%). This was followed by the lack of adequate medical information or assistance (63.3%), difficulties in coordinating healthcare appointments (46.7%), insufficient community or social support (43.3%), and lack of family support (26.7%). Most caregivers (83.3%) perceived physiotherapy to have a positive impact on the child's overall health, attributing improvements to maintained physical abilities and prevention of complications. However, (13.3%) remained neutral and (10%) believed physiotherapy had no impact. Challenges in communication and coordination with medical staff or physiotherapists were reported by (80%) of respondents, while (20%) stated they did not face such difficulties. The key challenges experienced by caregivers of children with SMA are illustrated in Figure 1

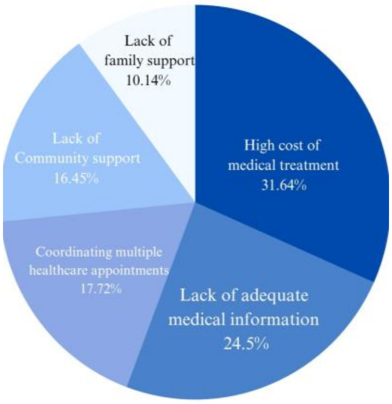

Figure 1

3.c Practice

Physiotherapy was universally practiced by all respondents (100%), either independently or under professional supervision. The frequency of physiotherapy sessions varied, with (40%) of caregivers reporting once-a-week sessions, (30%) providing therapy daily, (16.7%) three times per week, and (13.3%) twice per week. Home-based physiotherapy was preferred by the majority (73.3%), followed by specialized therapy centers (13.3%) and hospital-based settings (10%).

Caregivers identified several benefits of physiotherapy. Most respondents (70%) believed it improved functional status, while (63.3%) felt it enhanced overall quality of life. A total of (60%) reported that physiotherapy helped maintain joint mobility and flexibility, and (40%) cited its benefit in improving respiratory function. Additionally, (20%) viewed it as helpful for pain management, while (3.3%) noted its role in keeping muscles active. The timing of therapy initiation also varied among participants: (33.3%) began physiotherapy immediately after diagnosis, (16.7%) within one week, another (16.7%) within a month, (23.3%) within three months, and (10%) after more than three months. Specific barriers encountered in the physiotherapy management of children with SMA are depicted in Figure 2.

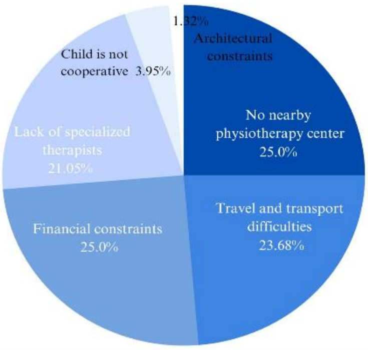

Figure 2

3.d Barriers and Support Needs

Caregivers reported multiple barriers in the provision and continuation of physiotherapy services. The most common barriers included a lack of nearby Physiotherapy centres' (63.3%) and financial constraints (63.3%). Travel and transportation issues were reported by (60%), and (53.3%) highlighted a lack of access to trained or specialized physiotherapists. Additional difficulties such as child non-cooperation (10%) and environmental concerns—like inadequate infrastructure, cleanliness, or inaccessible therapy spaces—were cited by (3.3%).

When asked about support services needed to optimize care, caregivers highlighted a range of requirements. The most frequently mentioned was access to medications and ongoing treatment (80%), followed by financial assistance (70%). Additional needs included respiratory care and equipment (56.7%), assistive devices and mobility aids (50%), educational accommodations (43.3%), counselling services (36.7%), and access to peer support groups (23.3%).

These findings provide a comprehensive picture of caregivers' knowledge, attitudes, and practices in managing children with SMA. They underscore the importance of physiotherapy while revealing the systemic, logistical, and emotional challenges that caregivers face—pointing to the need for enhanced multidisciplinary support to improve functional outcomes and quality of life.

4. Discussion

The present study demonstrates that caregivers of children with Spinal Muscular Atrophy (SMA) possess a reasonably good understanding of the condition, with most correctly identifying it as a hereditary neuromuscular disorder. Despite this, access to reliable and comprehensive information was reported as limited. Despite reliance on physicians and online resources, a significant proportion of caregivers lacked adequate disease-related information. Structured education through validated digital platforms and targeted community outreach are warranted. Such initiatives can help ensure consistent and accurate knowledge of disease mechanisms, therapeutic options, and long-term management strategies [1,3,6].

Caregivers in the present study displayed a generally positive attitude toward physiotherapy, recognizing its role in enhancing the functional abilities of children with SMA. Many acknowledged that regular physiotherapy supports mobility, independence, and overall quality of life. However, this favourable perception often did not translate into consistent access to therapy due to systemic limitations. Barriers such as high treatment costs, limited access to trained professionals, and unavailability of locally appropriate assistive devices were frequently cited. These challenges reflect global findings on SMA management and emphasize the need to integrate physiotherapy into primary healthcare systems [19,3,14]. Policies that promote subsidized therapy services, community-based rehabilitation programs, and mobile therapy units could play a significant role in bridging existing service gaps [6,14].

In addition, caregivers' perceptions of their children's quality of life were mixed. While some reported satisfactory physical and respiratory health, others raised concerns about their child's emotional well-being, independence, and opportunities for social engagement. These findings are consistent with previous studies showing the multidimensional burden of SMA on both children and their families [15,16,17]. A comprehensive care model that integrates physiotherapy with psychosocial support, peer interaction, and school-based inclusion programs is essential to address these broader quality-of-life dimensions. [18,19]

Furthermore, caregiver interactions with healthcare providers revealed important gaps in communication and coordination. Many caregivers experienced delays in therapy initiation and found it difficult to follow through on professional recommendations due to fragmented service delivery. Dedicated care coordinators, interdisciplinary follow-up teams, and the use of digital tracking systems for documentation and reminders could improve communication and ensure timely, continuous access to Physiotherapy. [5 6,7]

Although all respondents stated they provided physiotherapy for their children, there was considerable variability in how often and how consistently it was practiced. Many caregivers reported a preference for home-based physiotherapy, driven by barriers such as long travel distances, poor public transportation, and the physical toll of caregiving. While home-based approaches offer convenience, they often lack professional supervision. Tele-rehabilitation and caregiver training in home-based physiotherapy techniques could help maintain care continuity and improve treatment outcomes [7,10,13].

The study also highlighted cost as the most common and pressing challenge. Financial resources for families were severely stressed by costs associated with treatment sessions, mobility aids, medications, and transportation. Financial insecurity not only affected access to consistent care but also contributed to emotional stress and caregiver burnout. These findings support the global call for insurance-based or publicly funded models to support long-term rehabilitative care for chronic paediatric neuromuscular conditions [8,20,21].

Introducing targeted financial aid schemes for SMA-related rehabilitation would be a direct and impactful solution. Caregivers also emphasized the need for broader support systems, including timely access to medications, respiratory care, and assistive technologies. While pharmacological advancements like Nusinersen are promising, consistent physiotherapy and supportive care remain essential for optimizing treatment outcomes [14,24]. An integrated care model that prevents fragmentation and promotes coordination among specialties is critical for effective long-term SMA management.

Finally, the study revealed the psychological burden faced by caregivers. Many reported feelings of isolation, stress, and anxiety, often due to lack of support from family or the community. Recent findings confirm that caregivers of children with SMA frequently experience clinical levels of depression, anxiety, and poor sleep quality, necessitating psychosocial interventions [22]. These findings mirror those in other chronic paediatric conditions [19]. Establishing mental health services for caregivers, respite care options, and community-based awareness programs could help reduce this burden and foster shared caregiving responsibilities.

In summary, while caregivers of children with SMA show sound knowledge and favourable attitudes toward physiotherapy, multiple systemic and practical barriers limit its consistent implementation. Solutions such as integrated health policy reforms, tele-rehabilitation, caregiver education, and financial support systems are essential to make Physiotherapy more accessible and sustainable. A multidisciplinary, family-centered, and community-based model of care is vital for improving the functional outcomes and overall well-being of both children with SMA and their caregivers [15,16,17].

5. Limitations and Future Directions

Due to the low prevalence of SMA (approximately 1 in 10,000 live births), the study included only 30 purposively selected caregivers, limiting generalizability. Future research should include larger, more diverse samples and explore regional variations in healthcare access. Public health efforts should adopt a two-fold strategy: nationwide awareness campaigns and promotion of caregiver engagement with healthcare providers. Integration of physiotherapy within local healthcare systems, strengthened respiratory support services, and structured psychological counselling are recommended to enhance comprehensive care delivery.

Long-term studies on the effectiveness of tele-rehabilitation, home programs, and financial support models are warranted.

6. Conclusions:

Despite their strong understanding and enthusiastic attitude toward physiotherapy, caregivers of children with SMA frequently face practical obstacles that prevent them from receiving constant care. Addressing these through integrated health policies, tele-rehabilitation, and caregiver support is essential. A coordinated, family-centered approach is essential to improve both functional outcomes in children and well-being of their caregivers.

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