Factors Contributing to the Default in Neuro-Rehabilitation Programmes for Children with Chronic Neuro-Disabilities in the Largest Tertiary Care Hospital for Children in Sri Lanka

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ABSTRACT

Background: Neurorehabilitation is essential for optimising functional independence in children with chronic neurodisabilities. However, clinic default remains a significant barrier to achieving long-term health outcomes, particularly in resource-limited settings like Sri Lanka.

Objective: This study aimed to identify the socio-demographic, clinical, and systemic factors contributing to default in neuro-rehabilitation programs at the Lady Ridgeway Hospital for Children (LRH), Colombo.

Methodology: A descriptive cross-sectional study was conducted among 71 children with chronic neuro-disabilities who had defaulted from therapy services for over one year. Data were collected through interviewer-administered questionnaires covering socio-economic status, clinical condition, and perceived barriers to attendance.

Results: Most children who defaulted had Cerebral Palsy (67.6%), out of which, 68% were mobility dependent. 56.6% of the children who defaulted were from rural areas of the country. The average distance to the clinic was 106 Km. Key reasons for default were multifactorial: 66.2% cited financial problems, 64.8% reported receiving inadequate information on the importance of therapy, and 60.6% turned to alternative or indigenous treatments. Systemic barriers included long waiting times (53.5%) and transport difficulties (47.9%). Interestingly, 84.5% of caregivers had never received a follow-up call after defaulting. 73% of participants highlighted the importance of awareness programmes regarding the disease condition for them. While 61% identified telehealth as an alternative, 59% highlighted the importance of local support groups.

Conclusion: Default is driven by a lack of caregiver awareness and substantial socio-economic burdens. Improving retention requires decentralised care, enhanced caregiver counselling, and the integration of digital health solutions.

Keywords: Neurorehabilitation, Neurodisability, Clinic Default, Cerebral palsy, Paediatrics.

INTRODUCTION

Chronic neuro-disability in children encompasses a diverse range of conditions—including cerebral palsy, spinal cord injuries, and developmental delays- that necessitate long-term, multidisciplinary intervention. These conditions often require a holistic approach that includes physical, occupational, and speech therapies to maximize a child's physical, cognitive, and emotional development [1]. In Sri Lanka, the public health challenge is significant; according to the 2016 Sri Lanka Demographic and Health Survey (SLDAHS) report,

approximately 23% of children aged 2–5 experience at least one functional disability [2]. While neurorehabilitation aims to optimise a child's functional independence, its efficacy depends entirely on consistency and long-term participation [3]. While neurorehabilitation serves as the cornerstone of treatment for children with neurological impairments, its capacity to drive meaningful change is often undervalued and not yet fully grasped. Determining the precise impact of these interventions is a formidable task, as clinicians must distinguish the effects of therapy from the child's natural processes of neurological repair and continuous developmental growth. This complexity is further intensified by the absence of a standardised framework or "common language" to accurately describe and quantify the specific rehabilitation services a child receives [1,3].

Despite the availability of free tertiary healthcare in Sri Lanka, "clinic default"—defined in this study as a lack of attendance for over one year without prior notice—remains a persistent and complex issue. From a social science and public health perspective, default is not merely a medical failure or a lack of caregiver motivation; rather, it reflects systemic inequities, structural barriers, and caregiver burnout [4]. Families of children with chronic disabilities often navigate a landscape marked by social stigma, discrimination, and inadequate support services [5]. In low- and middle-income countries (LMICs), these challenges are magnified by limited resources and the unequal distribution of specialised care.

The social aspects of clinic default are deeply rooted in the family unit's socioeconomic fabric [6]. Families often face significant financial constraints and a lack of support from spouses or extended family, which can lead to domestic disharmony and family conflicts. Furthermore, the gendered nature of caregiving in many LMICs often places an immense burden on mothers, who may struggle to balance the intensive demands of neuro-rehabilitation with the needs of other children or household responsibilities [6,7]. Existing literature from the South Asian region, particularly India, suggests that distance to facilities, the perceived quality of hospital services, and inadequate patient education are primary drivers of non-compliance [8]. Globally, research has shown that financial constraints and a lack of social support are major contributors to default [9]. However, there is a notable gap in localized research in Sri Lanka examining the specific factors that lead to default among the paediatric neuro-disability population. This report explores these dynamics—identifying modifiable factors such as caregiver perceptions, transportation hurdles, and systemic clinic shortcomings—to inform more equitable and cost-effective public health policies.

Objectives

- To describe the socio-demographic characteristics of children with chronic neuro-disabilities who have defaulted from care.
- To identify the factors contributing to default across disease-related, therapy-related, clinic-related, and socio-economic domains.
- To assess caregiver perceptions on potential interventions that could have prevented default.

METHODOLOGY

Study Design and Setting

A descriptive research study was conducted at Lady Ridgeway Hospital (LRH) for Children in Colombo, the largest tertiary care paediatric hospital in Sri Lanka. The initial cohort was identified from patients registered at the LRH occupational and physiotherapy units from April 2023 to March 2024. This period was selected to avoid the effects of the COVID-19 pandemic on clinic follow-ups. Of 967 new registrations in this period, 154 patients had defaulted for more than 1 year (as of April 2025) without notice.

Inclusion Criteria: Children with long-term neurodisabilities requiring long-term physical, occupational and/or speech therapy, and who have been defaulted for more than 1 year were initially recruited.

Exclusion criteria:

- Children who were referred only for expert opinion at Lady Ridgeway Hospital or Children and are currently being followed up at local hospitals and receiving continuous therapy. (52 out of 154).
- Children who were not contactable to the study or whose contact details were not available at Lady Ridgeway Hospital for Children. (31 out of 154).
- Caregivers who refused to participate in the study.

Following exclusions (inability to contact or follow up at local hospitals), 71 participants were successfully recruited.

Data were gathered via interviewer-administered questionnaires conducted by the primary investigator. The tool assessed:

1. **Clinical Status:** This included the diagnosis of the neuro-disability, functional status of the child, including mobility, manual activity, communication and feeding, using Canchild.ca expanded and revised standardized scales [10].

2. **Socio-Demographics:** Parental age, Parental education, income, family dynamics, distance from house to clinic, transport logistics and allowances and social supports received.

3. **Behavioural Factors:** Beliefs regarding therapy, use of alternative medicine, reasons to default, and suggestions to improve clinic follow-up compliance.

Analysis was performed using SPSS version 27.0, utilizing frequencies, percentages, and mean/standard deviation for descriptive statistics.

RESULTS

Socio-Demographic Profile

The study analyzed 71 children who defaulted from neuro-rehabilitation services. The mean age of the participants was 91.63 months (approximately 7.6 years), ranging from 36 to 180 months. The gender distribution was relatively balanced, with 54.9% females and 45.1% males.

Socially, the family structure was predominantly stable, with 87.3% of children being cared for by both parents. However, educational and economic markers indicated significant vulnerabilities:

- Education: While most fathers (50.7%) and mothers (53.5%) reached a secondary level of education, only 4.2% of both parents had achieved tertiary or higher education.

- Occupation: Most fathers (63.4%) were engaged in non-skilled labour, and 64.8% of mothers were unemployed.

- Social Support: 70.4% of families received no government allowances, with only 9.9% accessing a disability allowance.

- Child Schooling: Notably, 33.8% of these children were not enrolled in any form of schooling.

		Frequency	Percent
Gender	Male	32	45.1
	Female	39	54.9
District of residence	Colombo	16	22.5
	Kaluthara	9	12.7
	Gampaha	6	8.5

Schooling status	Not schooling	24	33.8
	Pre school	5	7.0
	Primary school	21	29.6
	Secondary school	12	16.9
	Special school	9	12.7
Father's education level	Primary	1	1.4
	Secondary	36	50.7
	Tertiary	31	43.7
	Higher education	3	4.2
Father's occupation	Unemployed	1	1.4
	Non-skilled	45	63.4
	Skilled	19	26.8
	Professional	4	5.6
	Business	2	2.8
Mother's educational level	Secondary	38	53.5
	Tertiary	28	39.4
	Higher	3	4.2
Mother's occupation	Unemployed	46	64.8
	Non-skilled	12	16.9
	Skilled	7	9.9
	Professional	3	4.2

Table 1: Socio-demographic details of the study participants

Clinical Profile and Functional Levels

Cerebral Palsy (CP) was the primary diagnosis among 67.6% of the default cases. The most common subtype was Spastic Quadriplegic CP (28.2%), followed by Diplegic CP (18.3%).

	Frequency	Percent
Spastic Quadriplegic Cerebral Palsy	20	28.2
Diplegic Cerebral Palsy	13	18.3
Hemiplegic Cerebral Palsy	10	14.1
acquired hemiplegia / Stroke	4	5.6
Dystonia cerebral palsy	5	7.0
meningomyelocele	4	5.6
Neuropathy	4	5.6
Duchenne Muscular Dystrophy	1	1.4
Myopathy	1	1.4
Central hypotonia	7	9.9
Other	2	2.8

Table 2: Clinical diagnosis of the study participants

For the 48 children with Cerebral Palsy, functional limitations were assessed using standardized classification scales:

- Gross Motor (GMFCS): 25% were at Grade 5 (the most severe limitation, who are wheelchair-bound), while 29.1% were in Grade 4 and another 29.1% at Grade 3.
- Manual Activity (MACS): Functional hand use was severely limited (Grade 5) in 20.8% of cases.
- Communication: 52% were Grade 1, who are effective communicators with both familiar and unfamiliar people, indicating relatively effective communication compared to other domains.

- Eating/Drinking: 20.8% required significant assistance or were unable to swallow safely (Grade 5). They were on alternative feeding methods, including nasogastric or gastrostomy tubes.

	Gross motor		Manual activity		Communication		Eating and Drinking	
Grade	*n*	*%*	*n*	*%*	*n*	*%*	*n*	*%*
1	1	2	17	35.4	25	52	21	43.7
2	14	29.1	7	14.5	4	8.3	6	12.5
3	14	29.1	4	8.3	4	8.3	4	8.3
4	7	14.5	10	20.8	9	18.7	7	14.5
5	12	25	10	20.8	6	12.5	10	20.8

n – frequency, % - Percentage

Table 3: Functional status of the participants with cerebral palsy

Caregiver Perceptions and Satisfaction

All 71 children had received Occupational Therapy (OT) and Physiotherapy (PT) prior to defaulting. Satisfaction was measured on a 5-point Likert scale (1-Very Unhappy to 5-Very Happy):

- OT Satisfaction: Mean score of 3.69.
- PT Satisfaction: Mean score of 3.48.
- ST Satisfaction: Mean score of 3.43 (assessed for 35 participants).

This indicates that, even though defaulted, their experience with therapists and the service was satisfactory.

39.4% of caregivers reported never being counselled on neurorehabilitation by a healthcare provider. 43.7% were unsure whether therapy would improve their child's quality of life. 60.6% had turned to alternative, non-scientific therapies such as ayurvedic treatments, local remedies, and spiritual healing methods.

Geographic and Transport Factors

Participants were categorized by their district of residence to distinguish between urban and rural access. Urban Areas: Colombo (22.5%), Gampaha (8.5%), Kalutara (8%), Kandy (2.8%), and Galle (2.6%). Rural Areas: These accounted for approximately 56.6% of the sample, including districts like Ratnapura (8.5%), Badulla (5.6%), and Anuradhapura (4.2%).

Distance: The mean distance travelled to the clinic was 106.68 km, with a maximum of 360 km. Mode of Transport: 67.6% of families relied on the bus. Cost: The average cost per visit was 2,891.55 LKR (10 USD), with some families paying up to 18,000 LKR (60 USD).

		Amount per month	Frequency	Percent
Government allowances received	none		50	70.4
	Samudri	10 000 LKR (32.7 USD)	10	14.1
	Disability allowance	5 000 LKR (16.4 USD)	7	9.9
	Transport allowance	5 000 LKR (16.4 USD)	4	5.6
Mode of Transport	Public bus		48	67.6
	Train		7	9.9
	Hired Three-wheeler		7	9.9

	Own vehicle		7	9.9
	Rented vehicle		2	2.8
	Distance (Mean)	Distance (Median)	Distance (Max)	Distance (Min)
Distance from home to the clinic (Km)	106.68	80	360	5
	Cost (Mean)	Cost (Median)	Cost (Max)	Cost (Min)
Cost for a single clinic visit	2891.55 LKR (9.48 USD)	2000.00 LKR (655 USD)	300 LKR (1 USD)	18000 LKR (59 USD)

LKR – Sri Lankan Rupee, USD – United States Dollar

Table 4: Information on transportation to the clinics and expenses

Reasons for Clinic Default

Caregivers could select multiple reasons for disengaging from the clinic. The data highlights a heavy reliance on indigenous medicine and a significant lack of professional guidance. Financial problems were cited by 66.2% (47/71). 64.8% (46/71) did not receive adequate information on why therapy is important. 60.6% (43/71) tried indigenous options and spiritual healing methods. 53.5% (38/71) were not satisfied with extended waiting times at the clinics and identified this as a major reason for default. A summary of the common reasons for clinic default is illustrated in Figure 1.

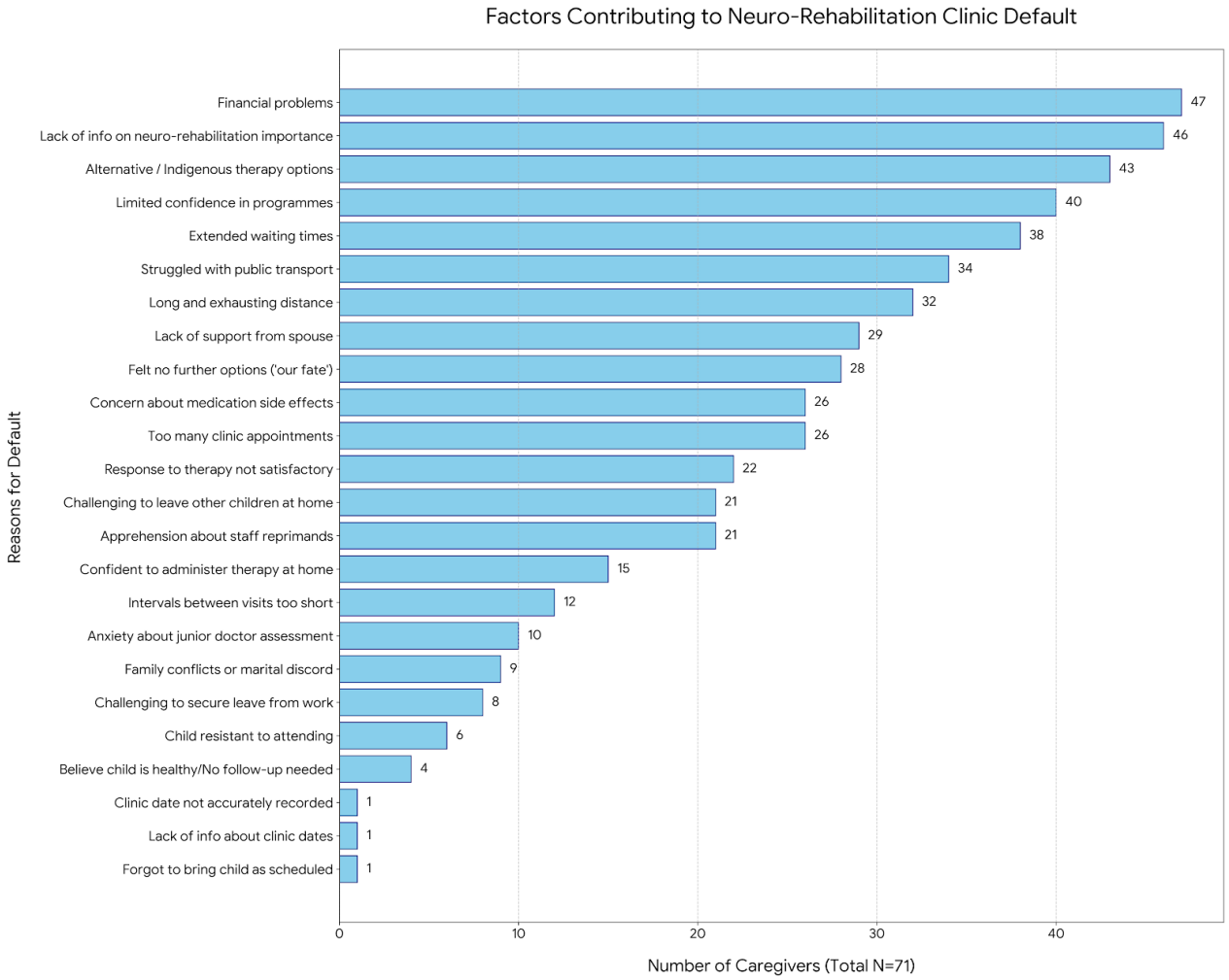

Figure 1: Factors contributing to neurorehabilitation clinic default, as selected by caregivers of defaulted children with neutralizabilities.

Caregiver Suggestions for Improvement

Caregivers identified several interventions that could have prevented their default, with a strong preference for localized and digital solutions. 73.2% (52/71) suggested awareness programs on the disease. Both Telehealth follow-ups and leaflets were requested by 62% (44/71) as alternatives to frequent clinic visits. They identify this as both financially advantageous and reducing caregiver burden and exhaustion. 60.6% (43/71) recommended community outreach programs at local Medical Officer of Health offices, which are field-level healthcare units. 59.2% (42/71) believed being part of a support group would improve participation through emotional support. A summary of the caregiver suggestions is illustrated in Figure 2.

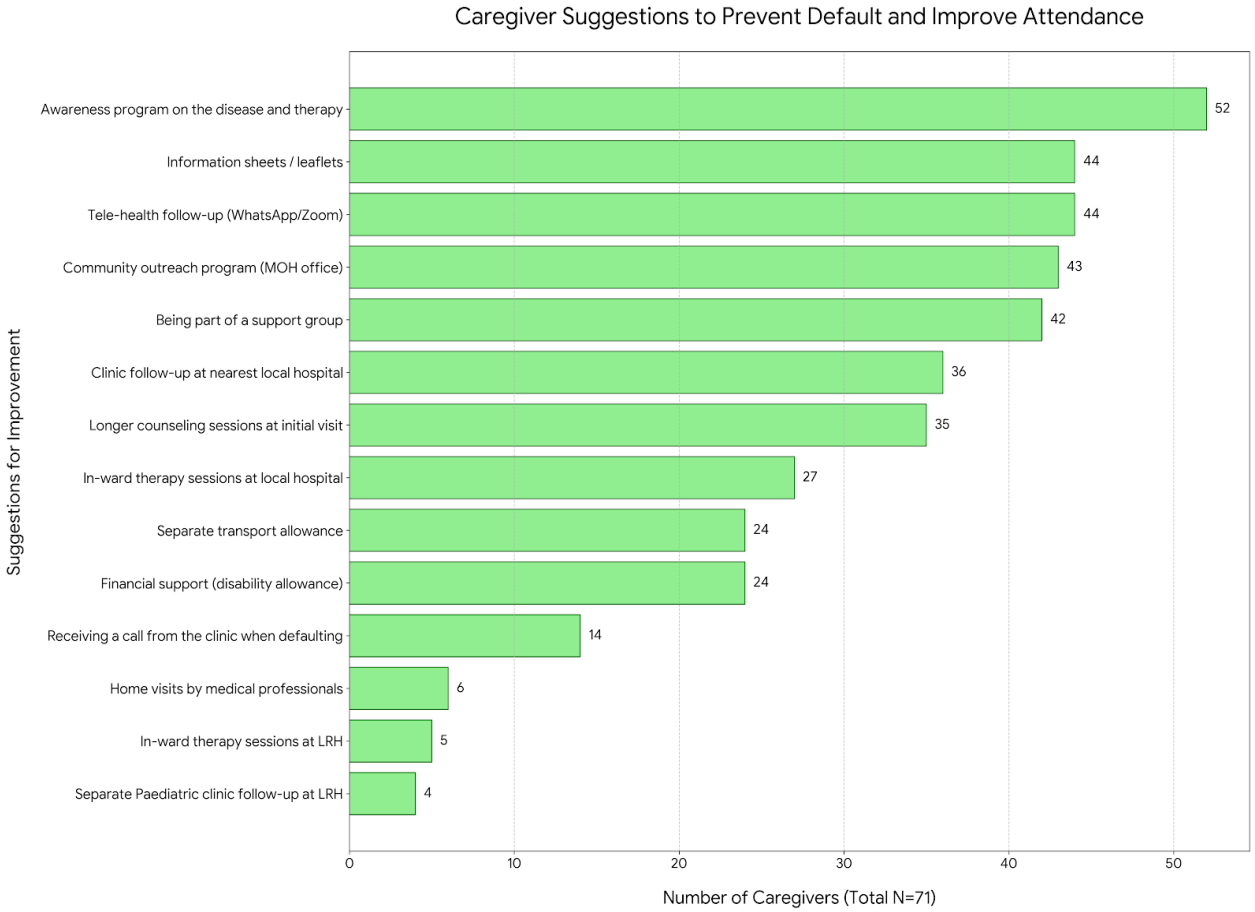

Figure 2: Caregiver suggestions to improve follow-up compliance at neurorehabilitation clinics at a Tertiary care hospital in Sri Lanka

DISCUSSION

The findings of this study provide a comprehensive look into the complex web of social, economic, and systemic factors that lead to clinic default among children with chronic neurodisabilities in Sri Lanka. From a social science and public health perspective, "defaulting" is rarely a simple choice made by a caregiver; rather, it is the result of a cumulative "caregiver burden" where the logistical and financial demands of seeking care eventually outweigh the family's perceived benefits and available resources.

The socio-economic paradox of "Free" healthcare:

Sri Lanka provides free tertiary healthcare, yet this study reveals that the "cost of access" remains a prohibitive barrier for the most vulnerable. While the medical consultations and therapies themselves are free, the ancillary costs—transportation, lost wages, and meals—create a significant financial strain. Access to reliable transportation is a fundamental social determinant of health, directly influencing how effectively individuals can use medical services [11]. In this study, caregivers identified a spectrum of transit-related obstacles—such as long travel times, high financial costs, and physical exhaustion from the journey—that frequently led to missed

clinical appointments. These barriers to essential healthcare resources do not affect all populations equally; they tend to have a disproportionate impact on families with lower socioeconomic status and those residing in underserved rural regions [12,13]. Such inequities are often the result of systemic factors, including the centralisation of specialised facilities in urban hubs, a lack of investment in regional infrastructure, and the high cumulative costs of long-distance travel [14].

The mean cost per visit of 2,891.55 LKR (approximately 10 USD) may seem modest in a global context, but for a population where 63.4% of fathers are non-skilled labourers and 64.8% of mothers are unemployed, these recurring costs are substantial. The economic burden of neurorehabilitation extends beyond direct travel expenses to include the significant "opportunity cost" of lost wages for the family. For caregivers in low-income brackets, particularly the 63.4% of fathers in this study who engaged in non-skilled labour, taking a day of leave to attend a clinic visit often results in a direct loss of daily income. This financial sacrifice is frequently unsustainable, forcing families to choose between a single day of therapy for their child and the basic nutritional needs of the entire household [15,16].

This economic vulnerability is compounded by a lack of social safety nets; 70.4% of the sampled families received no government allowances, and only 9.9% accessed a disability allowance. In low- and middle-income countries (LMICs), the lack of financial support often forces families to prioritize immediate household needs over long-term rehabilitation, which does not yield immediate "curative" results [17].

Geographic isolation and the centralization of care:

The centralization of specialized neurorehabilitation at the Lady Ridgeway Hospital (LRH) in Colombo creates a geographical divide. With 56.6% of defaulted participants residing in rural districts and travelling an average of 106.68 km, the physical toll of the journey is as significant as the financial cost. Relying on public buses (67.6%) to transport a child with severe motor limitations—such as the 25% of CP patients in GMFCS Grade 5 who are wheelchair-bound—is an exhausting ordeal.

47.9% of caregivers cited the struggle with public transport as a reason for default. This "distance decay" effect is well documented in public health, where service utilization decreases with increasing distance to the facility. For families in districts like Ratnapura or Badulla, a single clinic visit can consume an entire day (or more if an overnight stay is required), leading to "caregiver exhaustion". Because rural and remote residents must travel significantly farther and endure longer transit times to specialist neuro-rehabilitation services than to generalist care, the cumulative burden can become unmanageable. Consequently, travel time serves as a critical indicator of physical and mental fatigue, which ultimately drives many caregivers toward clinic default [18,19].

The information gap and the appeal of alternative medicine:

One of the most striking findings is the lack of effective communication between the healthcare system and the family. Nearly 40% of caregivers reported never being counselled on the importance of neurorehabilitation, and 64.8% felt they had inadequate information about why therapy was necessary. When the medical system fails to provide a clear roadmap or manage expectations, families often turn to culturally rooted alternatives [20].

The study found that 60.6% of families sought alternative therapies, including Ayurvedic treatments and spiritual healing. In the social context of Sri Lanka, these indigenous methods are often more "accessible"—not just geographically, but also emotionally. Healers often provide a sense of hope or a "cure" that the medical model, which focuses on long-term management and slow functional improvement, does not explicitly promise. This is reflected in the fact that 56.3% of caregivers were unsure or did not believe that therapy would improve their child's quality of life. Health professionals must adopt a patient-centred, culturally sensitive approach that recognises how deeply embedded cultural beliefs are in shaping health-seeking behaviours. By acknowledging and integrating these cultural perspectives, clinicians can better address the "spiritual fatalism" that leads many to accept disability as an unchangeable fate. Ultimately, bridging the gap between clinical expectations and traditional values is essential for fostering trust and ensuring long-term participation in paediatric rehabilitation programs in low and middle-income countries [21,22].

Systemic failures and the silent default:

The systemic pressures on tertiary care facilities in Sri Lanka are pivotal in explaining the high rates of clinic default observed in this study. While a staggering 84.5% of families were never contacted by the clinic after they defaulted, this lack of follow-up often stems from institutional constraints rather than individual negligence. The clinics at tertiary care hospitals are frequently overwhelmed by high patient volume, exacerbated by chronic staff shortages and inadequate infrastructure [23]. To provide intensive care, clinicians often provide close follow-up dates, which, while medically sound, can inadvertently increase the logistical and financial burden on the family.

Furthermore, the lack of comprehensive digitization remains a critical barrier; most records are maintained as hard copies, making it nearly impossible to implement automated "default trace" systems to identify and re-engage families who have missed appointments [24]. This is compounded by the fact that patients often bypass local facilities to seek care at tertiary centers because regional hospitals frequently suffer from a lack of staff and specialized sub-specialties [23]. Furthermore, 53.5% of caregivers identified extended waiting times as a major deterrent. For a parent who has already travelled over 100 km with a disabled child, waiting several hours in an overcrowded, understaffed tertiary center often becomes the final straw that leads to total disengagement from the healthcare system.

A path forward: Social and public health interventions

The caregiver suggestions provide a clear blueprint for reform. There is strong demand for decentralization and digitalization.

- Localized Care: 60.6% requested community outreach programs at local field-level health offices, which would eliminate the grueling journey to Colombo.
- Telehealth: 62% identified Telehealth and digital leaflets as viable alternatives that could reduce the financial and physical burden on the family.
- Emotional Support: 59.2% expressed a desire for support groups. In social science, peer support is a critical factor in building resilience [25]; knowing that other families face similar struggles can mitigate the "our fate" sentiment reported by 39.4% of caregivers.

Limitations

While this study provides a comprehensive look into the factors that are driving the clinic default, several limitations must be acknowledged:

- Sample Size: The final recruitment was 71 participants. A larger sample size would have increased the statistical power and generalizability of the findings to the broader population of children with neurodisabilities in Sri Lanka.
- The recall Bias: Data was collected through interviewer-administered questionnaires from caregivers who had defaulted for over one year. This time lapse may introduce recall bias, as caregivers might not perfectly remember specific clinical counselling sessions or the exact sequence of events leading to their disengagement.
- Single-Centre Design: The study was conducted exclusively at Lady Ridgeway Hospital in Colombo. Although LRH is the largest tertiary care pediatric hospital in the country, families' experiences here may differ from those at regional or base hospitals, where systemic pressures and resource allocations vary.
- Selection Bias: Families who were completely uncontactable (31 out of 154) were excluded. It is possible that these families faced even more severe barriers—such as extreme poverty or total lack of telecommunication access—that are underrepresented in the current data

CONCLUSION

Clinic default in paediatric neurorehabilitation is not merely a medical failure, but a complex social phenomenon driven by systemic inequities and caregiver exhaustion. This study confirms that while healthcare is "free" at the point of delivery in Sri Lanka, the "cost of access", comprising transportation, lost wages, and the physical toll of long-distance travel, remains a prohibitive barrier for the most vulnerable families. The findings highlight a critical gap in communication, where a lack of caregiver awareness and the absence of a structured follow-up system allow families to drift into permanent default.

To transform neurorehabilitation from a logistical burden into a sustainable pillar of child development, the following policy shifts are recommended:

- **Decentralization of Services:** Shift from a Colombo-centric model to a localized care approach by integrating rehabilitation services into field-level Medical Officer of Health (MOH) offices and regional hospitals.
- **Implementation of Digital Health Solutions:** Utilize Telehealth for routine counseling and follow-ups to reduce the frequency of grueling physical journeys to tertiary centers.
- **Structured Caregiver Support:** Establish a "Default Trace" system using simple telephone follow-ups and formalize counseling at the point of diagnosis to ensure parents understand the long-term necessity of therapy.
- **Expansion of Social Safety Nets:** Policy should move toward targeted financial support, such as dedicated transport allowances or expanded disability benefits, to ensure that immediate household needs do not force families to sacrifice their child's long-term functional independence.
- **Community-Based Integration:** Encourage the formation of local support groups to mitigate the psychological burden of caregiving and address "spiritual fatalism" through peer resilience and emotional support.

Declarations

Ethics Approval

Ethical approval for this study was granted by the Ethics Review Committee (ERC) of the Sri Lanka College of Paediatricians.

Consent to Participate

Informed written consent was obtained from the primary caregivers or legal guardians of all individual participants included in the study.

Funding

Personal funding was used for the project.

Author contributions

All authors contributed to the study's conception, design, and execution. All authors participated in the drafting and editing of the manuscript. All authors have read and approved the final manuscript.

Conflicts of interest

The authors declare that there are no conflicts of interest.

Data availability

To protect participants' privacy and personal information, the datasets generated and analyzed during this study are not publicly available. However, anonymized data can be provided to the editorial board upon reasonable request from the corresponding author.

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