



Qualitative exploration into therapeutic itinerary of children with physical disabilities in Nigeria using thematic content analysis

Exploração qualitativa do itinerário terapêutico de crianças com deficiência física na Nigéria usando análise de conteúdo temática

Exploración cualitativa del itinerario terapéutico de niños con discapacidades físicas en Nigeria utilizando análisis de contenido temático

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Submitted on 09/09/2020.

Accepted on 01/29/2021.

DOI:<https://doi.org/10.1590/2177-9465-EAN-2020-0361>

ABSTRACT

Objective: To explore the therapeutic itinerary for seeking care for children with physical disabilities by caregivers. **Methods:** A descriptive qualitative design recruiting nine consenting caregivers of children with physical disabilities attending a Nigerian Teaching Hospital. A semi-structured interview guide was used to collect data on therapeutic itinerary which was defined as the paths taken by individuals to address their health problem. Interviews were audio-recorded and transcribed verbatim. Data was analyzed using thematic content analysis. **Results:** Emerging themes revealed that caregivers commenced therapeutic itinerary for their children upon observation of any impairments that go beyond casual illnesses. Lack of capacity in private hospitals, which serves as initial point of entry into care seeking, encourage vacillation into public hospitals, spiritual homes, and traditional clinics. Entry into physiotherapy was dependent on self-referrals, referrals by relatives, and physicians. Caring for children with physical disability significantly affected caregiver's social life, finances, work; and unmet expectations for a child to get well as soon as possible encouraged continuous pluralism. **Conclusion and implications for the practice:** Having children presenting with impairments and delayed milestones led to complex multiple health care seeking practices among caregivers. Thus, these caregivers become medical pluralists and covertly non-adherent to hospital treatment prescriptions.

Keywords: Therapeutic Itinerary; Caregivers; Children; Physical Disabilities; Nigeria.

RESUMO

Objetivo: Explorar o itinerário terapêutico na busca de cuidados para crianças com deficiências físicas pelos cuidadores. **Métodos:** Um plano qualitativo descritivo que recrutou nove cuidadores de crianças com deficiência física, com consentimento, que frequentavam um Hospital Universitário Nigeriano. Foi utilizado um guia de entrevista semi-estruturado para coletar dados sobre o itinerário terapêutico, que foi definido como os caminhos percorridos pelos indivíduos para resolver o seu problema de saúde. As entrevistas foram gravadas em áudio e transcritas literalmente. Os dados foram analisados utilizando a análise do conteúdo temático. **Resultados:** os temas emergentes revelaram que os cuidadores iniciaram o itinerário terapêutico para os respectivos filhos após a observação de quaisquer deficiências que vão para além de doenças casuais. A falta de capacidade dos hospitais privados, que servem como ponto inicial de entrada na busca de cuidados, encorajou a procura por cuidados nos hospitais públicos, lares espirituais, e clínicas tradicionais. A entrada na fisioterapia dependia de auto-referências, referências por parentes e médicos. Cuidar de crianças com deficiência física prejudicou de modo significativo a vida social, as finanças, o trabalho do cuidador; e expectativas não alcançadas de que a criança melhorasse o mais cedo possível encorajaram um pluralismo contínuo. **Conclusão e implicações para a prática:** O fato de ter crianças com deficiências e de ter havido atraso nos progressos levou os cuidadores a práticas múltiplas e complexas na busca de cuidados de saúde.

Palavras-chave: Itinerário Terapêutico, Cuidadores, Crianças, Deficiências Físicas, Nigeria.

RESUMEN

Objetivo: Explorar el itinerario terapéutico para la búsqueda de cuidado de niños con discapacidad física por parte de los cuidadores. **Métodos:** Un diseño cualitativo descriptivo que recluta a nueve cuidadores de niños con discapacidades físicas que asisten a un hospital universitario de Nigeria. Se utilizó una guía de entrevista semiestructurada para recopilar datos sobre el itinerario terapéutico que se definió como los caminos que recorren los individuos para abordar su problema de salud. Las entrevistas fueron grabadas en audio y transcritas textualmente. Los datos se analizaron mediante análisis de contenido temático. **Resultados:** Los temas emergentes revelaron que los cuidadores iniciaron un itinerario terapéutico para sus hijos al observar cualquier impedimento que vaya más allá de las enfermedades casuales. La falta de capacidad en los hospitales privados, que sirve como punto inicial de entrada en la búsqueda de atención, fomenta la vacilación en los hospitales públicos, hogares espirituales y clínicas tradicionales. La entrada en fisioterapia dependía de las autorremisiones, las derivaciones de familiares y médicos. El cuidado de niños con discapacidad física afectó significativamente la vida social, las finanzas y el trabajo del cuidador; y las expectativas no satisfechas de que un niño se recupere lo antes posible fomentaron el pluralismo continuo. **Conclusión e implicaciones para la práctica:** El hecho de que los niños presentaran discapacidades e hitos retrasados condujo a múltiples prácticas complejas de búsqueda de atención médica entre los cuidadores. Por lo tanto, estos cuidadores se vuelven médicos pluralistas y encubiertamente no se adhieren a las prescripciones de tratamiento hospitalario.

Palabras clave: Itinerario Terapéutico; Cuidadores; Niños; Discapacidades Físicas; Nigeria.

INTRODUCTION

The Global Burden of Disease estimated that nearly 15% of the world population has moderate or severe disability.¹ Of the affected population, about 93 million of them are children aged ≤14 years have varying degrees of disabilities.² The society attach stigma to children with physically disability in Africa.³ As such, the burden of living with disability does not only affect the child but their caregivers. Consequently, caring for a child with physical disability is one of the most stressful events that can occur.⁴ Particularly, children with disability generally increases parent's vulnerability to stress affecting mothers more.^{5,6} Caring for children with physical disability can be physically and mentally exhausting, due to demands of caring for them around the clock and their complex health care needs.^{7,8} Caregivers of children with physical disabilities are more likely to experience depression and distress than caregivers of children without disabilities.⁹ However, the magnitude and the nature of challenge face by parents and caregivers depend on the severity of physical disabilities.¹⁰ Some of the prominent needs reported by their parents are related to personal care,¹¹ management of adaptive behaviours,¹² medical,¹³ technical, financial and social needs.¹⁴ Thus, having children with physical disabilities put a significant burden on the caregivers to initiate care seeking which purposely or inadvertently set them on multiple complex paths.

The paths taken by individuals to solve their health problem is referred to as therapeutic itinerary.¹⁵ Often children with physical disability and their families require interventions from different services, such as health, education, social services,¹⁶ and sometimes seek interventions outside the orthodox practice.¹⁶ Therefore, understanding therapeutic itinerary of caregivers of children with disabilities have significant policy implications,¹⁶ with respect to providing affordable access to health care, multi-agency support, emotional and psychological support, and respite for parents of children with disabilities.¹⁷⁻¹⁹ Caregiving is not a static event or a single behaviour but a complex dynamic process that unfolds over time and this further underscore the dynamic complexities of care giving processes.²⁰ These call for exploring therapeutic itinerary of children with disabilities to inform improvement in policy decision making and meeting the several aspects of help and support for these children.

Though, about 7% of Nigerian children reported neurological disabilities, the health care system in Nigeria is weak and provides sub-optimal care and support needed by these children.²¹ Anecdotally, parents of children with disability in Nigeria, embark on different types of overt and covert health journeys, in search of care for their children. Consulting traditionalists (native doctors) for children with disability may be informed by poverty and culture-based stereotypes implying that such children are signs of gods punishment which makes parents medical pluralist (i.e. consulting multiple sources including traditionalists and spiritual homes) in seeking help for their children with physical disabilities.^{22,23} This medical pluralism engaged may delayed access to rehabilitation care and thus, outcomes may be sub-optimal. Thus, therapeutic itinerary of parents and caregivers

of children with disability needs to be explored to inform policy decision making. Unfortunately, these practices seem not yet put in empirical perspective. Therefore, this study explored the therapeutic itinerary for seeking care for children with physical disabilities by caregivers.

METHODS

This descriptive qualitative study recruited consenting caregivers of children with physical disabilities attending the Children Outpatient Physiotherapy Clinic at a Nigeria University Teaching Hospital. Eligible respondents were parents/caregivers of children with physical disabilities who were within the ages of 10 and 14 years. As suggested by Creswell,²⁴ 5-25 informants as required for a qualitative study. Therefore, this study recruited nine available parents/caregivers. In the setting where the study was conducted, first contact to rehabilitation services including physiotherapy was not common. Children with physical disability which often required rehabilitation services comes through physician referral. The authors pre-conceived opinion that older children with disability would have experience substantial therapeutic itinerary informed the choice of 10-14 years old children and moderated by the interview format that allowed open-ended dialogue from the research participants.

A semi-structured interview guide was used to collect data on therapeutic itinerary. The purpose of the study was fully disclosed to the participants, their rights to participate or not, and assured protection of their identities in data storage and reporting were emphasized. Thereafter, their signed informed consent to participate in the study was obtained. Also, permission was sought to tape record the interviews. One of the authors (OAT) conducted the interviews in noise free cubicle and each interview took about 15 minutes. Interviews were conducted in either English or Yoruba depending on participants' language of best proficiency. Yoruba language is the most spoken indigenous Nigerian language in the setting of this study. Translation of interviews in the Yoruba language into English was done by experts at the Department of Linguistics and African Languages of a Nigeria University.

The tape-recorded interviews were transcribed verbatim to guarantee accuracy. Short descriptive codes were allocated to sections of the text, then codes expressing similar concepts were grouped together to form themes. Deductive thematic content analysis of key themes and phrases were used to organize data and narrations were presented.²⁵ Peer debriefing was done during analysis to limit the potential biases associated with the positionality of the interviewing author. Themes were reviewed and audited to ensure that they were grounded in the transcripts and well represented within the data with adequate examples thereby increasing the trustworthiness of the study. An audit trail also assisted in reducing bias in the study. Descriptive statistics of frequency, percentages were used to summarize data on the socio-demographic variables of the participants, and the summary of the qualitative analysis.

An ethical approval of the study was obtained through Ethics and Research Committee of the Obafemi Awolowo University Teaching Hospital Complex (ERC/2019/12/14).

RESULTS

The participant’s demographic characteristics shows that above half of mothers have three/more children and seek help late (55.6%) (Table 1). Figure 1 shows the path taken seeking care for children with physical disabilities. The mothers expressed various path seeking care for their children with physical disability. Table 2 shows emerged category, theme and sub-theme. The qualitative analysis results from the study are presented in italics.

Risk factors for physical disability

Pregnancy history is one of the valid ways of evaluating prenatal risk factors for impairment in children. Therefore, this study explored the prenatal history of the children with disability. While a majority of the mothers reported that their pregnancies were not associated with any major circumstance, others reported a few incidences for which interventions were sought. A mother reported:

there was nothing much that surrounded his conception, I was not sick during the pregnancy, in fact, I do go for regular check-ups at the hospital, the scan confirmed the baby was doing fine in the womb (P1).

At the same time incidences of being unwell during the pregnancies were narrated by some of the mothers as captured by a mother:

... I didn’t even know I was pregnant because I was still menstruating as at then, the doctor later confirmed that I was 2months pregnant, I did the ultrasound of the pregnancy, I was still very ill, my mother in-law gave me some herbs, and I was fine (P8).

The study explored caregivers recalls on whether the pregnancy was eventful or not. A few of the mother recants that their pregnancies were uneventful. A mother retorted:

I gave birth to him when the pregnancy was nine months, and it was not through caesarean section but normal delivery. After I gave birth to him, he cried by himself, the nurse didn’t beat him before he cried, I can say he was hale and hearty (P1).

However, other recalled their eventful experiences:

I gave birth to him in a traditional clinic after a prolong labour of two days (P5).

Table 1. Physical characteristics of the respondents and summary of child’s therapy record.

Variable	N
Socio-demographic characteristics of respondents	
Marital Status	
Married	9
Profession	
Teacher	2
Fashion designer	1
Caterer	3
Trader	3
Number of Children	
One	2
Two	2
Three	2
Four	3
Family Setting	
Monogamous	6
Polygamous	3
Summary of child’s therapy record	
Radiological investigation	
Yes	8
No	1
Regular Check-ups	
Yes	8
No	1
Eventful birth	
Yes	6
No	3
Noticeable features of child	
Sick	2
Delay Developmental Milestone	5
All of the above	2
Immediate step taken when child’s condition was noticed	
Went to hospital	2
Sought advice	2
Sought alternative therapy	3
All of the above	1
None of the above	1
Different path taken in search of care	
Went to hospital	3
Sought alternative therapy	1
All of the above	5
Immediate response to hospital care	
Early	3
Late	5
Not specific	1

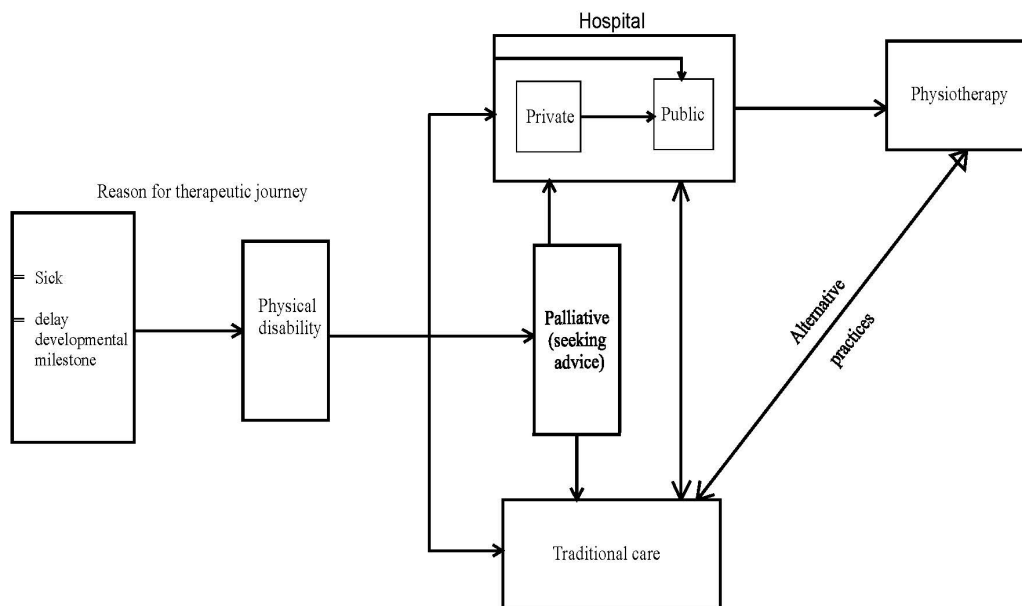


Figure 1: Path taken by the study respondents while seeking for care for children with physical disabilities.

Table 2. Category, theme and sub-theme emerged from the study.

Category	Theme	Sub-theme
Risk factors for physical disability	· Pregnancy history	· Sickness during pregnancy
	· Eventful pregnancy	· Prolong labour · Pre-term birth/delivery · Neonatal illness/sickness
Triggers of therapeutic itinerary and therapeutic actions	· Child’s welfare	· Strange illness/sickness · Delayed milestone
	· Impediment and impairment	· Body paralysis
	· Pluralism of therapy	· Physician consultation
		· Traditional healers
	· Spiritual homes	
· Facilitator of therapeutic itinerary	· Child’s health uncertainty · Perception of alternate therapy · Access to care	
Rehabilitation experiences	· Rout to physiotherapy	· Physician referral · Self-referral through enquiry
	· Satisfactory and helpful	· Less waiting times · Affordable consultation and treatment fee
Burden of therapeutic itinerary on caregiver	· Social/emotional isolation	· Depression
		· Loss of wages/job · Low quality of life
	· Barrier seeking care	· Time, work and distance constraint

I gave birth through caesarean section when he was 8 months after a prolong labour of almost two days (P7).

In sum, most of the mothers went through harrowing prolonged labour ranging from 8 hours to 3 days. In addition, pre-term deliveries were more reported than post-term births. None of the cases of caesarean deliveries was elective but emergency to save the mother and/or the child.

Triggers of therapeutic itinerary and therapeutic actions

The therapeutic itinerary of the mothers concerning their children seems to commence upon mothers' observations of impediments and impairments that go beyond casual illnesses that affect children. Typically, among some mothers, it began as early as when the child was a neonate to many months postpartum. The triggered were varied as highlighted:

he could not crawl, stand, he was always bending forward, no neck control (P4).

almost all the joints of his body were very stiff and he couldn't use them, it was like my baby was paralyzed already (P7).

The therapeutic actions taken included consultation with physicians, starting from Primary Health care to Teaching Hospital, traditional healers and spiritual homes. Some informants revealed:

I took him to one matron on my street. I took him to Primary Health Centre. He was later referred to this facility [Teaching Hospital], and later referred for physiotherapy (P4).

I told my mum about it, she took me to a traditional bone setter clinic for treatment" (P7). I took her to church for prayer, I was in in church with her for months (P9).

These also confirmed the multiple practices of the mothers:

the places have gone to seek for medical care for her include; church, hospital and there was a time my elder sister took me to a traditional healer (P9).

In the attempt to unravel the undercurrents for medical pluralism that exist among mothers in this study, referral pattern, wait times for initial consultations and the barriers to seeking health care at the Teaching Hospital where this study was conducted was explored. The findings indicate that direct access to care, self-referral practices, and vacillations were common. Direct access to care was most noticeable in the patronage to the private setting and Primary Healthcare Centre. An informant narrated:

Actually when the incident happened, I rushed her to a private hospital (P3).

Typically, other forms of practices involving self-referral and other forms of referrals, as well as vacillation between and among different modes of care generate after these initial points of call. In asserting to referral practices, the informants state:

What happened was, I had taken her to the General Hospital before coming down to this place, I came here by myself (P2).

And in other instances, referrals came from the first point of call to the Teaching Hospital:

He was referred from that hospital [Private] to the Teaching Hospital for further treatment (P3).

Rehabilitation experiences

The mothers narrated their experiences with the first and subsequent consultations saying:

When we got here, I was first directed to the children emergency ward and from there he was referred to physiotherapy (P5).

The mothers relish their experiences as generally satisfactory in terms of affordability of consultation fee and reasonable wait time for consultation and treatment:

It was really pleasant because they attended to him on time, the consultation fee was not too high (P1).

Overall, the mothers affirmed that their visits to the hospital have been helpful. Some of the excerpts relay this view:

So far it has been helpful because have been seeing some changes in the child ever since have been bringing him to this hospital (P1).

It has been helpful, have seen several changes in her and improvement because she couldn't sit well before (P2).

The route into physiotherapy for the rehabilitation of the children was mapped. In most cases, doctors referred the mothers for physiotherapy for their children's conditions.

Doctor was the one that referred him for physiotherapy (P4).

Others made self-enquiries and self-referred for physiotherapy:

I started physiotherapy for her myself, I was not referred here, so I came for physiotherapy by my own discretion (P2).

For some of the patients, physiotherapy was commenced early at the same time some of these mothers have been bringing their children for quite a while.

I started physiotherapy early for him (P1).

And for some others, physiotherapy was started late owing to a number of reasons:

I started physiotherapy for her late because of money and some other personal things (P9).

Burden of therapeutic itinerary on caregiver and barrier seeking care

Care seeking for children with physical disabilities have been reported to disrupt caregivers' lives, especially the mothers. We explored how and to what extent the therapeutic itinerary of the caregivers has interfered with their lives. The except reveal the positions of a mother:

The child's condition has so much interfered with the family, it has not been easy, many times am always depressed, it has really affected my social life, most times I don't even attend social gatherings, have not been able to do most things i am supposed to be doing, but I'm trying to do them now (P1).

Engaging in alternative practice is often influenced by a number of factors ranging from personal factors to peer pressures. Relations, friends and persons of influence guided the decisions of most of the caregivers.

My husband, family friends and the people around me, actually influenced some of the decisions I took on my child (P2).

Literature is replete on barriers to seeking care in public health facilities. One of the consequences of such barriers is that it engenders alternative practices. The caregivers narrated the major setback as following: finance, time constraints, work/job constraints, distance constraints, transportation issues, and social problems.

A lots of setbacks and constraints, like financial constraints, time constraints and a lot of things like that are standing as a constraint in the care giving of the baby... distance is another big issue for me because I bring my baby from a very far distance just for treatment here (P4).

DISCUSSION

This study explored the therapeutic itinerary for seeking care for children with physical disabilities by caregivers. The children

in this study were heterogeneous in characteristics as they present with various forms of disabilities. Typically, literature assert that disability in children often presents with a myriad of impairment which might involve cognitive, sensory, motor, social or communications/language aspects singly or in combination.²⁶

Good care during pregnancy is important for the health of the mother and the development of the unborn baby.²⁶ Pregnancy is a crucial time to promote healthy behaviours and parenting skills. Good antenatal care links the woman and her family with the formal health system, increases the chance of using a skilled attendant at birth and contributes to good health through the life cycle. Inadequate care during this time breaks a critical link in the continuum of care and affect both women and babies.²⁷ A third of all pregnant women in this study experienced illness during pregnancy, of which some required hospitalisation. Studies have shown that preventing problems for mothers and babies depends on an operational continuum of care with accessible, high quality care before and during pregnancy, childbirth, and the postnatal period. It also depends on the support available to help pregnant women reach services, particularly when complications occur. It is plausible that the precursors of the physical disabilities in the children may have been averted.

From this study about a third of mothers recalled that their pregnancy was eventful. For some of the mothers, patronizing traditional clinics to give birth, after prolonged labour and things got out of hand, they vacillated to the conventional hospitals as the alternative. Patronage and preference for traditional birth attendants (TBA) is still rampant in most developing countries like Nigeria. Amutah-Onukagha et al.³ reported that despite advances in modern healthcare, TBA has continued to be heavily utilized in rural communities in Nigeria. Typically, TBAs are providers who are traditionally independent of the health system and are community-based providers of care during pregnancy, childbirth and the postnatal period.²⁸ TBAs do not receive formal medical training when compared to other health professionals such as obstetricians and gynecologists. However, TBAs are much more affordable and accessible than skilled birth attendants (SBAs) in most parts of the country.²⁹ Due to the lack of education in some TBAs, the way many attended the delivery is risky for women and their babies, leading to poor health outcomes and even death.³⁰

The aftermath of eventful pregnancies and complications from delivery on the part of the baby is impairment, delayed milestone and disability. Specifically, from this study, more than half of children presented with delay developmental milestone. Delay in developmental milestone often get parents worried and embark on care seeking. Studies have summarized that once a developmental concern arises, many factors effect parents' help-seeking responses including personal qualities (self-efficacy, knowledge, skills, energy, and persistence), peer and family influences and norms, and expectations that their actions will be fruitful.³¹⁻³³ Past experiences of interactions with primary care or other formal supports (treatment by the agency and feeling respected by the provider) strongly affect help seeking

and service use decision-making, as do trust, family and cultural norms, stigma, and self care practices.^{34,35}

These aforementioned reasons in addition to child's health uncertainty, perception of other therapy and access to care as identified by the present study triggered and facilitated therapeutic itinerary of children with physical disability. As reported in a previous study, it is likely that parents see the condition of their children as emergency and were in desperate search of resolution.³⁶ It is not unlikely that perception of spiritual homes and traditionalists as offering helps to health challenges promoted facilitation between these providers and orthodox medical care.²³ It is also noteworthy that some caregivers were not satisfied with care or received sub-optimal care from health facility and thus, made them in search of 'better alternative care'. It might be that the health professionals they first consult are less qualified and thus, could not provide optimal care as suggested by a previous study.³⁶

From the current study, it was found that parents of children with physical disability do not adapt well to the conditions of their children. In previous studies, it was found that there is considerable variation in how parents adapt to care giving demand.^{37,38} Some do not adapt well to the challenges of caring for a child with a disability because negative consequence posed by increased physical attention on them.^{39,40} In low-income countries, many caregivers of children with disabilities contend with poverty, limited public services and lack assistive devices. In these situations, care giving may require more physical work than in high-income countries and so carry greater risk of physical injury or health problems.⁴¹ Thus, the role of care giving can be stressful and has been found to negatively influence the health and wellbeing of caregivers.^{40,42} The findings of this survey show that the caregivers whose children had severe level of physical disability, the level of dependence of the child on the other members of the family is very high as observed previously.^{10,43} Generally, mothers of children with physical disability have little time for themselves, either because of the demands of childcare or because they choose to spend much of their time with their child with a physical disability⁴⁴ and they describe negative, physical, emotional and functional health consequences of long-time, informal care giving.⁴⁵ These observations are in agreement with present study that therapeutic itinerary of caregivers of children with physical disability is a big burden on them and often imposes a social and emotional burden for children and the families.^{46,47}

Mothers reported finance and social stigma as most implicated setback into receiving care from hospital facilities. This problem of low parents' income is further compounded by the additional cost of raising a child with a disability,⁴⁸ as well as a loss of previous social networks and stigma.⁴⁹ In low and middle-income countries, social and environmental factors related to the situations in which people with disabilities and their families live, influence the complex interactions between disability, poverty and health.²² This make caregivers engages in multiple care-seeking practice for their children.⁵⁰

It is important to acknowledge that this was a study of group of children with disability receiving rehabilitation in physiotherapy unit of a single hospital. The extent to which the findings might have wider implication beyond this setting is one of the limitation of the study.

CONCLUSION AND IMPLICATIONS FOR THE PRACTICE

Having children presenting with impairments and delayed milestones precipitates complex multiple health care seeking practices among caregivers. Hence, the caregivers become medical pluralist of conventional and traditional practices and this may promote conflicting or non-adherence to treatment.

AUTHOR'S CONTRIBUTIONS

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