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Between beliefs, traditional practices, and modern care: Parental perceptions in the management of paediatric chronic diseases

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ABSTRACT

Introduction

In the Democratic Republic of Congo (DRC), perceptions of paediatric chronic illnesses remain strongly shaped by cultural and spiritual beliefs. These beliefs influence care-seeking behaviours and treatment adherence. However, few studies have explored the lived perceptions of families in Kinshasa.

Purpose

To explore the beliefs, traditional practices, and expectations of families regarding the hospital management of paediatric chronic illnesses.

Methods

An exploratory qualitative study was conducted with 10 parents or guardians of children hospitalised for chronic illness at the University Hospital Centre Renaissance in Kinshasa. Semi-structured interviews were conducted in French or Lingala to collect their experiences. Data were analysed using Braun and Clarke's six-phase inductive thematic approach, validated through double coding, and interpreted within the framework of Leininger's transcultural theory.

Results

Three main themes emerged. Most parents (7 out of 10) attributed their child's chronic illness to supernatural causes such as curses, witchcraft, or divine testing. More than half (6 out of 10) first used traditional or religious remedies before seeking hospital care, with family and community support playing a central role. Although some participants acknowledged the effectiveness of medical treatment, several reported financial constraints, insufficient attentive listening, and weak communication from healthcare providers. A majority of families (8 out of 10) expressed a strong need for respect for their beliefs, involvement in decision-making, and recognition of their knowledge and traditions.

Conclusions

Parental perceptions directly influence treatment pathways. Integrating families' beliefs and expectations into the care relationship is essential to strengthen therapeutic adherence. The study highlights the need for a culturally sensitive approach, including community mediation, intercultural communication training for healthcare professionals, and family-centred therapeutic education.

INTRODUCTION

In the Democratic Republic of Congo (DRC), paediatric hospital care is confronted with a wide range of cultural interpretations and traditional practices that strongly influence how families respond to illness. When a child is affected by a chronic condition, the understanding of the disease, therapeutic decisions, and adherence to treatment are shaped not only by medical explanations but also by local beliefs, family traditions, and spiritual prescriptions. Cultural representations largely influence healthcare choices and shape the relationship with medical institutions (Dikuyi, 2013).

At the University Hospital Center Renaissance of Kinshasa, a referral facility that receives families from diverse sociocultural backgrounds, parental perceptions often diverge from the biomedical model. Such representations may clash with modern medical approaches, creating tensions in the caregiver–patient relationship (Ezembe, 2009). Yet few studies in Kinshasa have examined in depth how parents of children with chronic illnesses perceive these conditions, the traditional practices they use, and their expectations regarding hospital care. This gap represents a significant blind spot in the literature.

Many families continue to interpret illness as the result of a spiritual imbalance, divine punishment, or a community curse (M'Bemba-Ndoumba, 2016). These beliefs often lead to the use of rituals, traditional remedies, or spiritual consultations—sometimes alongside hospital care (Mvone-Ndong, 2008). While culturally meaningful for families, such practices may generate misunderstandings and communication breakdowns with healthcare providers, particularly when professionals lack the conceptual and relational tools to address them (Nkulu, 2014).

Family expectations extend well beyond the delivery of medical treatment. They include recognition of their lay knowledge, respect for their beliefs, and attention to the quality of interactions with healthcare staff. Acknowledging these dimensions fosters trust and engagement (Wamba, 2016; Verdier, 2019). When expectations are ignored, mistrust and disengagement may follow; however, dialogue and listening can transform families into active partners in care (Samba, 2018).

In this context, it is concerning that the University Hospital Center Renaissance of Kinshasa still lacks systematic mechanisms to identify and integrate such representations into its care organisation. There is a need to adapt healthcare practices to the multicultural realities of the capital city (Ramazani & Muhinduka, 2018).

To analyse this phenomenon, Madeleine Leininger's transcultural nursing theory, developed in the 1970s, was adopted as the theoretical framework. This approach emphasises the role of values, beliefs, and cultural practices in providing culturally appropriate nursing care (Nzamba, 2012). In Kinshasa, it offers a useful perspective for examining how tailoring care to the sociocultural characteristics of families can optimise the management of paediatric chronic illnesses.

From this standpoint, a central question arises: **How do families perceive a child's chronic illness, what traditional practices do they use, and what expectations do they have regarding hospital care?** Addressing this question is crucial to strengthening treatment adherence, improving care quality, and developing culturally sensitive interventions. It is within this perspective that the present study is situated.

METHODS

Study Design

This research adopted a qualitative exploratory approach aimed at gaining an in-depth understanding of the cultural representations, traditional practices, and expectations expressed by families of children hospitalised with chronic illnesses. This method enabled the exploration of meanings attributed to illness, healthcare, and interactions with the hospital system in a context deeply influenced by cultural values (Camara, 2023).

Study Setting

The study was conducted at the Centre Hospitalier Universitaire Renaissance of Kinshasa (CHURK), a referral institution located in the Congolese capital. The centre receives patients from diverse sociocultural backgrounds, making it an appropriate setting for analysing cultural dynamics within family–care relationships.

Participants and Sampling

The study population consisted of parents or guardians of children with chronic illnesses. Participants were selected using purposive sampling. Eligibility criteria required that parents or guardians of hospitalised children with chronic conditions (such as sickle cell disease, diabetes, or asthma) be the child's primary caregiver, have at least one week of hospital experience, and freely consent to participate. Participants were chosen to reflect diversity in socioeconomic, educational, and religious backgrounds to capture the plurality of representations.

Sample Size

The study involved 10 parents or guardians of children hospitalised for a chronic condition. This small sample size is consistent with qualitative research, which prioritises depth and richness of data rather than statistical representativeness. In qualitative studies, sample size is determined by data saturation—the point at which no new significant information emerges (Naeem et al., 2024; Ahmed, 2025). In this study, saturation was reached by the eighth interview and confirmed with the remaining two participants.

Data Collection Methods

Data were collected using an interview guide structured around three main themes:

1. Cultural and spiritual representations of the child's illness
2. Traditional practices employed before or during hospitalisation
3. Expectations regarding care, caregiver–patient relationships, and the healthcare system

Individual semi-structured interviews were conducted in French or Lingala, lasted 30–60 minutes, and were held in a quiet and confidential environment. All interviews were audio-recorded with informed consent and transcribed verbatim.

Data Collection Process

Data Recording

Interviews were recorded using a smartphone after informed consent. Recording ensured accuracy, reduced omissions, and preserved linguistic nuances, thereby strengthening data reliability.

Data Transcription

All recordings were transcribed verbatim, capturing pauses, hesitations, and key expressions. This process enabled rigorous coding and thematic identification.

Data Translation

Interviews conducted in Lingala were translated into French by the primary researcher. A second bilingual researcher reviewed the translations. Discrepancies were discussed until consensus was reached, ensuring credibility and cultural accuracy.

Data Analysis

The data were analysed using Braun and Clarke's (2006) six-phase inductive thematic analysis: familiarisation, coding, theme development, review, definition, and report writing. Double coding was carried out by two researchers, and discrepancies were resolved through discussion.

The analysis was guided by Leininger's Transcultural Nursing Theory (1970), which integrates cultural beliefs into healthcare to strengthen therapeutic relationships.

Scientific Rigour and Bias Reduction

Scientific rigour was ensured through credibility (triangulation, data saturation), transferability (contextual description), dependability (audit trail), and confirmability (researcher reflexivity and use of verbatim quotes).

Ethical Considerations

The study adhered to ethical principles of confidentiality, anonymity, and informed consent. Participants were informed of their rights, and all transcripts were anonymised (PS1–PS10). The protocol received approval from the Ethics Committee of the Institut Supérieur des Techniques Médicales de Kinshasa.

RESULTS

Findings on Parents' or Guardians' Perceptions and Experiences in Managing Chronic Illnesses

Sociodemographic Characteristics

Ten parents or guardians were interviewed. Their sociodemographic profile is summarised in **Table 1**.

Table 1:
Sociodemographic Characteristics of Interviewed Parents/Guardians (PS = Participant; M = Male; F = Female)

No.	Sex	Age	Education	Marital Status	Religion	Occupation	Income	HH Size	Relation	Duration of Follow-up	Child Age	Other Sick Children
PS1	F	35	Secondary	Married	Christian	Self-employed	Medium	6	Mother	2 yrs	8 yrs	No
PS2	M	28	Primary	Single	Christian	Unemployed	Low	5	Father	6 mths	4 yrs	No
PS3	F	41	University	Married	Christian	State employee	High	4	Mother	5 yrs	10 yrs	Yes
PS4	M	33	University	Married	Christian	Self-employed	Medium	6	Father	1 yr	6 yrs	No
PS5	F	46	None	Widow	Christian	Unemployed	Low	3	Mother	3 yrs	12 yrs	Yes
PS6	M	51	University	Married	Christian	State employee	High	5	Father	10 yrs	14 yrs	No
PS7	F	39	Secondary	Single	Christian	Self-employed	Medium	6	Mother	4 yrs	9 yrs	No
PS8	F	25	Primary	Single	Christian	Unemployed	Low	4	Mother	8 mths	3 yrs	No
PS9	M	44	University	Divorced	Christian	Self-employed	Medium	3	Father	6 yrs	11 yrs	No
PS10	F	30	Secondary	Married	Christian	State employee	Medium	6	Mother	1 yr	7 yrs	No

Participants were predominantly women aged 25–51 years. Most were Christians, married, and living in households of five or more members. Educational attainment ranged from no formal schooling to university level. Income levels were generally low to medium. All were biological parents, and most had been managing the child's illness for fewer than five years. Two participants reported having other sick children.

Findings on Parents' Perceptions and Experiences in the Management of Chronic Illnesses

Theme 1: *Understanding and Interpretation of Chronic Illness*

Sub-theme: Representations and Beliefs

Belief in Witchcraft or Curses

The majority of parents (7 out of 10) attributed their child's chronic illness to supernatural causes, including witchcraft, curses, or occult forces. These beliefs strongly influenced their healthcare-seeking behaviours.

One parent stated, *"I thought the illness came from a curse cast according to our traditions."* (PS1).

Another directly attributed the illness to occult practices: *"It's the work of sorcerers..."* (PS2).

Other testimonies reinforced this view:

"In our community, when a child falls sick like this, we say someone is behind it." (PS3)

"This is not an ordinary illness; it is something hidden." (PS4)

"We believed it was a curse that struck our family." (PS5)

"In our community, such things are often explained by witchcraft." (PS7)

"I was convinced that an evil spirit had caused it." (PS9)

These accounts show that supernatural interpretations are dominant and shape families' initial responses, often delaying recourse to biomedical care.

Belief in a Divine Trial

A majority of parents (6 out of 10) perceived the illness as a divine trial, which influenced the way they accepted and managed the situation.

One parent described the illness as a spiritual test: *"I understood it as a trial sent by invisible forces to test us."* (PS6).

Another expressed religious resignation: *"I accepted that it was God's will; there is nothing we can do about it."* (PS4). Others stated:

"God decides everything; we must accept it." (PS10)

"We prayed and accepted that this illness is a test of our faith." (PS7)

"The illness is a trial sent by God to strengthen us." (PS8)

"We believe that God tests us to teach patience and perseverance." (PS9)

These narratives show how framing the illness as a divine trial shapes families' perceptions, coping strategies, and care decisions.

Theme 2: *Resort to Traditional Practices and Dialogue with Healthcare*

Sub-theme: *Parallel Care Strategies*

Use of Remedies and Spiritual Practices

Most parents (6 out of 10) reported first resorting to traditional or spiritual care before seeking hospital treatment.

One parent explained: *"Traditional remedies are part of our culture; we always start with them."* (PS1).

Another described reliance on religious support:

"Before going to the hospital, we consulted the pastor who prayed for the child." (PS8).

Other accounts included:

"My neighbour helped us with local remedies that relieved the child while waiting for the hospital." (PS4)

"We first tried the medicinal plants we know, as we always do in our family." (PS2)

"We took the child to a traditional healer before going to the hospital." (PS6)

"We preferred to pray and use holy water before seeking hospital care." (PS9)

These accounts show that traditional and spiritual practices are prioritised, influencing the timing of biomedical intervention.

Family and Community Support

Half of the parents (5 out of 10) highlighted the importance of moral, spiritual, and financial support received from family and community members.

Examples included:

"My family members supported us a lot by bringing meals and taking care of the other children." (PS1)

"The pastor came to pray with us at the hospital, and that comforted us." (PS2)

"My brothers and sisters contributed money to pay for some medicines." (PS3)

"The neighbours came to visit us and helped us take the child to the hospital." (PS4)

"The fact that my family was always present gave me courage to face my child's illness." (PS5)

These accounts show that family and community support are crucial resources in the illness experience.

Theme 3: *Tensions Between Medical Recommendations and Cultural Practices*

Sub-theme: *Agreement/Disagreement with Healthcare Providers*

Disagreements Between Families and Healthcare Providers

The majority of parents (7 out of 10) reported tensions between medical advice and cultural or family expectations, which often complicated adherence to treatment.

Examples included:

"My family wanted me to stop the medicines and give only herbs, but the doctor advised me to continue." (PS1)

"It is not easy to balance family beliefs and medical care, but I chose to trust healthcare professionals while keeping my convictions." (PS4)

"The hospital no longer wants us to continue with local remedies." (PS7)

"My parents insisted that I consult a healer, while the doctors said the opposite." (PS2)

"My husband wanted to rely on prayers only, but the doctor warned me of complications if we stopped the treatment." (PS5)

"I was torn between listening to my in-laws or following the medical prescriptions." (PS6)

"We agreed to continue the treatment, but at the same time my family demanded prayers and traditional remedies." (PS9)

These testimonies show that cultural disagreement is common and may delay full adherence to biomedical care.

Theme 4: *Relationship and Communication with Healthcare Professionals*

Sub-theme: *Care Experience and Listening*

Reported Negative Experiences

Most parents (6 out of 10) reported frustrations linked to poor communication, lack of listening, or perceived disregard for their beliefs.

Examples included:

"They just gave me the prescription without explaining anything; I was really lost." (PS1)

"Healthcare providers only take care of the things they studied at school." (PS7)

"Sometimes you feel a certain rejection when we talk about our traditions." (PS8)

"I felt that my beliefs were not taken seriously by the medical staff." (PS2)

"The staff did not want to hear about the traditional remedies we use." (PS3)

"I was frustrated because no one explained what I could do at home to help my child." (PS6)

These accounts reveal that negative experiences largely stem from a lack of cultural sensitivity, which affects trust and adherence.

Positive or Mixed Experiences

A minority of parents (4 out of 10) described positive or mixed interactions with healthcare providers.

Examples included:

"They do not judge our beliefs; they respect them, which creates a good atmosphere." (PS5)

"Sometimes they even try to adapt the care to our cultural expectations." (PS9)

"Some nurses take the time to listen to our beliefs and respect us, but others do not." (PS4)

"One nurse explained the treatments while taking our traditions into account, which reassured me." (PS10)

These accounts show that culturally responsive communication strengthens trust and cooperation.

Theme 5: Expectations and Recommendations of Parents/Guardians

Sub-theme: Expressed Needs

Need for Respect and Participation

The majority of parents (8 out of 10) wanted their beliefs to be acknowledged and to be actively involved in decision-making.

Examples included:

"We want our beliefs to be respected, even if they are not shared." (PS1)

"We want to be listened to and involved in decisions regarding our children." (PS7)

"It is essential that the staff understand and respect our traditions during treatment." (PS2)

"We want to be informed and consulted before any medical decision is made." (PS3)

"Our experiences and knowledge of local remedies should be acknowledged." (PS4)

"We wish for healthcare providers to engage with us and understand our perspective." (PS5)

"Even if we do not share the same view as the doctor, respect is essential." (PS6)

"Being involved in decisions reassures us and strengthens our trust in the treatment." (PS8)

These accounts show that parents expect respect, dialogue, and shared decision-making.

Material and Educational Needs

Most parents (6 out of 10) recommended improved medical equipment and better health education for families.

Examples included:

"More modern medical equipment is needed to better treat the children." (PS1)

"Education sessions about the illness would help families manage the situation better." (PS8)

"More instruments and medicines would help reduce complications in children." (PS2)

"It would be useful for families to learn how to recognise warning signs and act quickly." (PS3)

"Better equipped and clean rooms would reassure families." (PS4)

"Families should regularly receive information on the prevention and management of the illness." (PS6)

These accounts show that parents want both material improvements and ongoing educational support.

DISCUSSION

Sociodemographic Characteristics of Parents and Guardians

Most of the parents or guardians interviewed were women (biological mothers) aged 25 to 51 years, with a secondary level of education and living in households of five to six members. Many work in the informal sector and have low income. The duration of follow-up for the child's chronic illness ranged from a few months to ten years, indicating long-term involvement in disease management. These findings align with the work of Boussari et al. (2023), who highlight the central role of mothers in the care of children in Central Africa.

This responsibility places a considerable psychological and material burden on mothers, who often manage daily care alone. It generates persistent stress, particularly in periods of economic uncertainty, as shown in research on psychosocial disorders among caregivers of patients with chronic illnesses (Epikmen et al., 2022). The absence of formal institutional support worsens these constraints, increasing mothers' need for information, home-based follow-up, and psychosocial assistance.

The analysis further shows that cultural and traditional beliefs are not limited to parents with low educational levels but are present across all social groups. Non-biomedical practices should not be interpreted as a simple "lack of education" but as legitimate cultural expressions that should be acknowledged and integrated into the care relationship (Côté, 2024).

Parents' Perceptions and Experiences in Managing Chronic Illnesses

The results indicate that parents often associate their child's illness with supernatural causes (e.g., curse, divine punishment, spell), shaping their initial reactions to the diagnosis—shock, fear, and denial—and influencing care-seeking behaviours. These interpretations are consistent with explanatory models that view illness as a transgression of social or spiritual order (Davoine & Salamin, 2022). As a result, families follow pluralistic care pathways, where biomedical treatments are not automatically prioritised.

The use of traditional healers, medicinal plants, pastors, or rituals is common, either before or alongside hospital care. This therapeutic pluralism is linked not only to belief systems but also to social and economic factors such as accessibility, proximity, and trust. These findings echo the work of Godbout (2023) and Gross (2024), who note that in African contexts, families mobilise all available resources to cope with illness, even when doing so may conflict with biomedical care.

Hospital experiences are ambivalent: families appreciate the dedication and professionalism of the healthcare staff, yet they criticise the lack of explanations, poor communication, and limited consideration of their beliefs. The exclusion—explicit or implicit—of cultural practices creates feelings of alienation and increases distrust toward the biomedical system, thereby weakening the therapeutic relationship.

Parents emphasised their desire to be recognised as active partners in care rather than passive recipients. It is therefore essential to establish a trusting and lasting relationship based on cultural recognition, support, dialogue, and respect (Kasenda et al., 2024; Landry et al., 2024).

The expectations expressed—open dialogue, cultural mediation, staff training, access to medication, and improved infrastructure—reflect the World Health Organization's (2015) recommendation to adapt health systems to the needs of vulnerable populations. Integrating these elements into hospital strategies is a key lever for improving quality of care in multicultural settings.

CONCLUSION

This study highlights the complexity of family representations, traditional practices, and expectations surrounding paediatric chronic illnesses, shaped by deeply rooted spiritual, social, and community factors. These dimensions influence how illness is understood, the care pathways chosen, and the quality of interactions with healthcare professionals.

The findings reveal that families do not inherently oppose hospital care but expect their beliefs to be respected, their knowledge recognised, and their needs heard. Cultural recognition emerges as a key factor in building trust and promoting active participation in the child's care.

The study suggests integrating families as partners in care, valuing their experience, role, and culture. Implementing cultural mediation tools, adapting educational messages, and creating listening spaces are practical strategies to promote truly family-centred and culturally sensitive paediatric care.

This research contributes to a deeper understanding of the interactions between family beliefs and biomedical care in the Congolese context and offers practical guidance for improving the quality of chronic paediatric care. Limitations include the study's focus on a single hospital setting and a small sample size, which may restrict generalisability.

Future actions should include developing and evaluating training programmes for healthcare personnel, integrating cultural mediation frameworks into hospitals, and promoting respectful, participatory communication with families to ensure sustainable, equitable, and humane paediatric care.

Recommendations

Based on the study findings, the following actions are recommended to improve paediatric chronic care in a culturally sensitive manner:

- Create listening and dialogue spaces for families in hospitals.
- Encourage active family participation in the child's care.
- Develop culturally adapted educational materials.
- Promote respectful dialogue between biomedical and traditional practices.
- Involve community leaders in awareness activities about modern healthcare.
- Implement staff training on cultural competence.
- Monitor and evaluate the implementation of these interventions.

Ethical Approval: The protocol received approval from the Ethics Committee of the Institut Supérieur des Techniques Médicales de Kinshasa.

Conflicts of Interest: None declared.

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