Editorial

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It takes a village: reimagining patient centricity for rare disease families in low- and middle-income countries

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"In LMIC contexts, patient centricity must be understood not as an individualized concept, but as a collective and relational model of care."

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"*It takes a village to raise a child.*"

This widely cited African proverb reflects a longstanding recognition of collective responsibility embedded within many societies. Its relevance extends beyond cultural philosophy, offering a powerful lens through which patient centricity can be re-examined – particularly in the context of rare disease care in low- and middle-income countries (LMICs).

In high-income settings, patient centricity has largely evolved around the individual: their autonomy, preferences and lived experience. In LMIC contexts, however, such an individualized framing is often insufficient. Patients exist within deeply interconnected social systems where care is shared, decisions are collective, and wellbeing is shaped by community structures. For families affected by rare diseases, these social networks are not peripheral – they are essential to survival.

Reframing patient centricity in context

Patient centricity is widely recognized as a cornerstone of high-quality healthcare and an ethical imperative in health system design. The WHO has emphasized the importance of placing people, and critically, communities, at the center of healthcare delivery through integrated, people-centered systems [1].

However, translating this principle into practice requires contextual adaptation. In LMICs, rare disease care unfolds within social ecosystems that extend far beyond the individual. Illness affects not only patients, but also families, caregivers, and, in many cases, entire communities. Rare diseases are associated with substantial psychosocial and economic burdens, including stigma, barriers to care and reduced social participation [2].

Within these environments, the impact of a rare diagnosis is rarely contained. Emotional strain, caregiving responsibilities and financial pressures frequently diffuse across extended family networks. Cultural interpretations of illness – often shaped by religious beliefs or local traditions, further influence how care is sought, understood and sustained [3].

Health system models designed for high-income contexts often assume access to specialized services, stable infrastructure and individual autonomy in decision-making. These assumptions are frequently misaligned with realities in LMICs. Instead, care is often maintained through informal networks: families develop expertise, neighbors provide support and community figures – including traditional healers, play meaningful roles in health-seeking behavior. Traditional and complementary medicine remains an integral component of care for many populations, particularly where it is more accessible and culturally aligned [4].

Acknowledging these dynamics is not optional, but essential for designing patient-centered approaches that are both effective and contextually appropriate.

Expanding the scope of advocacy

In this context, advocacy for patient centricity must extend beyond the individual patient voice. It requires a broader, more inclusive understanding of who constitutes 'the patient' in LMIC settings.

Care is frequently co-produced by a network of individuals: parents, extended family members, educators, community health workers and informal caregivers. Their contributions shape diagnostic pathways, treatment adherence and long-term outcomes. Patient-centered frameworks must therefore evolve toward community-inclusive models that recognize collective responsibility and shared decision-making [5].

This shift aligns with global calls to strengthen community engagement in healthcare and move toward more participatory, locally grounded models of care delivery.

Barriers to patient-centered care in LMIC rare disease contexts

Despite growing recognition of the importance of patient centricity, several structural and contextual barriers continue to limit its implementation.

Health systems not designed for complexity

Health systems in many LMICs are primarily configured to address high-burden infectious diseases such as malaria, tuberculosis and HIV. Rare diseases (often complex, chronic and multisystemic) do not fit easily within these frameworks. Consequently, they receive limited attention in national health strategies, with insufficient funding, infrastructure and policy support [6].

Limited awareness & recognition

Rare diseases remain under-recognized, contributing to prolonged and fragmented diagnostic journeys. Evidence suggests that patients experience significant diagnostic delays, often involving multiple consultations and misdiagnoses [7]. In LMICs, where access to diagnostic technologies is more limited, these delays are likely to be more pronounced.

Economic vulnerability

The economic impact of rare diseases extends far beyond direct medical costs. Financial strain associated with travel, lost income and long-term care can destabilize entire households and communities. In such contexts, immediate survival needs may take precedence over sustained healthcare engagement [8].

Cultural barriers & trust dynamics

Healthcare interventions that do not align with local belief systems may face resistance or limited uptake. Traditional healers and faith-based practitioners often play central roles in community healthcare, influencing perceptions of illness and treatment pathways. Integration of culturally appropriate approaches, including traditional medicine, is increasingly recognized as important in strengthening health systems [9]. Language barriers, literacy levels and trust dynamics further affect engagement with formal healthcare systems.

Limitations of existing research frameworks

Global research methodologies often prioritize individual-level data and standardized instruments, which may not translate across diverse cultural contexts. Widely used tools such as the EQ-5D and SF-36, while valuable in high-income settings, may fail to capture contextually relevant aspects of quality of life in LMIC populations [10,11]. This highlights the need for more culturally and contextually sensitive research approaches.

Addressing the evidence gap

A significant gap remains in the global evidence base on patient centricity in LMIC rare disease contexts. Much of the existing literature is derived from high-income settings and reflects assumptions that may not hold in resource-constrained environments.

Rare diseases affect an estimated 300 million people worldwide yet remain underrepresented in research and policy discussions [12]. Key areas requiring further exploration include:

- The role of community networks in sustaining care;
- The impact of stigma and belief systems on health-seeking behavior;

- Collective decision-making processes within families;
- The broader socioeconomic effects of rare diseases;
- Regional variation in disease presentation and management.

Without this evidence, efforts to implement patient-centered care risk remaining incomplete or misaligned with the needs of affected populations.

Conclusion

In LMIC contexts, patient centricity must be understood not as an individualized concept, but as a collective and relational model of care. Rare disease experiences are embedded within families and communities, where care is shared and shaped by social, cultural and economic realities.

Reimagining patient centricity in these settings requires a fundamental shift, from focusing solely on individuals to recognizing the interconnected systems that sustain them. Only through such an approach can patient-centered care become truly inclusive, equitable and effective.

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