Cystic Fibrosis Transition from Pediatrics to Adult Care in Low-Middle Income Countries

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Abstract

As survival improves for individuals with cystic fibrosis (CF) worldwide, the number of adolescents requiring transition from pediatric to adult care is rapidly growing. In addition to limited resources, lack of uniform access to medical care, access to traditional and advanced therapies, the increasing number of transitioning young adults in low- and middle-income countries (LMICs) face barriers and challenges to safe transition from pediatric to adult healthcare that are both universal and unique. This shift in demographics presents distinct challenges due to underdeveloped and under-resourced adult CF care infrastructure, sociopolitical variation, and cultural complexities. This manuscript focuses on healthcare transition (HCT) of people with CF (pwCF) in LMICs, identifies key barriers, and explores cultural, religious, and health system factors. Additionally, we emphasize the practical need to transition adolescents to adult care to maintain pediatric hospital capacity for younger children, as well as the developmental and educational needs of young adults entering a medical system that is challenging for adults without chronic disease. With much of the transition literature reflecting health systems in high-income countries (HIC), this integrated socio-ecological and socio-cultural overview underscores the urgent need for context-specific, culturally sensitive transition frameworks focused on reproductive and mental health, the integration of adolescent-responsive, family-inclusive, and even faith-informed care models in LMICs.

Cystic Fibrosis Transition from Pediatrics to Adult Care in Low-Middle Income Countries

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this integrated socio-ecological and socio-cultural overview underscores the urgent need for context-specific, culturally sensitive transition frameworks focused on reproductive and mental health, the integration of adolescent-responsive, family-inclusive, and even faith-informed care models in LMICs. Key words: cystic fibrosis, healthcare transition, pediatric to adult healthcare, low-middle-income-countries, resource-limited, resource-denied, adolescent-responsive care

Introduction

Global shifts in CF survival and demographics The majority of people with cystic fibrosis (pwCF) in high-income countries (HIC) are now adults 1-4. This shift reflects the advances in diagnosis, early intervention and development of therapies that stabilize, if not reverse disease progression with advent of CFTR modulators, even for those who are not eligible or do not tolerate CFTR modulators. However, these advances are unevenly distributed worldwide.

Persistent inequities in diagnosis and treatment in LMICs The longstanding false perception of CF as a condition associated with predominantly white European-descended populations, has led to delays in recognition and referral, diagnosis, and deprioritized resource allocation of CF specific therapies across many LMICs, including Africa and Southwest Asia 28. This framing based on racial biases in medicine have shaped how CF is understood, skewing funding decisions, diagnostic algorithms, and genetic testing panels toward HIC and white European CFTR gene variants. As a result, while HICs and some upper-middle-income countries benefit from robust diagnostic and treatment infrastructure, many LMICs still lack access to sweat chloride testing altogether, and CFTR genetic testing is often limited to mutation panels that fail to capture the variants most common to local populations. Once CF is diagnosed, LMICs lack regular access to even decades old therapies and especially new therapies that require region specific genetic testing to determine eligibility and allocation of resources from financially strapped ministries of health 5. Despite these difficulties, there are still a growing number of individuals with CF in LMICs surviving into adulthood whose care needs are not being met.

Rational for focusing on Healthcare Transition (HCT) in LMICs While transition to adult care is a well-studied and yet still problematic process in HICs, LMICs face unique barriers that remain underexplored. Transition is particularly critical in LMICs, where pediatric care centers are often overburdened, and adult services often remain fragmented or underdeveloped. Munyikwa et al. recommend transition models be responsive to local systems, advocate for disability rights and equity among populations intersecting with marginalized groups, and emphasize collaboration between health, education and social sectors 23. Furthermore, adults with CF not only require ongoing management of respiratory complications but have also been found to experience higher rates of non-pulmonary comorbidities at younger ages, necessitating close health surveillance during transition period 6. A better understanding of the demographics of CF in LMICs and a focus on the needs of adolescents and young adults with CF within the context of their home regions and informed by the region's social and financial resources will allow local and countrywide allocation of resources to meet the complex needs of these individuals who strive for the same level of life expectancy as those in HICs.

Objectives and framework of this review We aim to synthesize available evidence on HCT for pwCF in LMICs to identify key barriers impeding effective HCT and to propose the development of context-specific, culturally responsive frameworks to guide HCT in LMICs. Recognizing that transition is shaped not only by individual and health system factors but also by broader social and cultural contexts, we will employ a hybrid framework that integrates the Social-Ecological Model (SEM) with the Social-Cultural Model (SCM) (Figure 1). This approach will allow us to analyze barriers and facilitators across multiple levels – from individual and family to community, cultural, and policy – while also attending to the cultural meanings, norms, and values that influence care. Ultimately, we seek to propose context-specific, culturally responsive frameworks to guide HCT in LMIC settings.

Review structure We conducted a structured literature review to identify and synthesize published evidence on HCT for individuals living with CF in LMICs (Table 1). We searched PubMed and Google from inception to August 4th, 2025, using Medical Subject Headings (MeSH) and free-text terms related to "cystic fibrosis," "healthcare transition," and "low- and middle-income countries." Conference abstracts and presentations at scientific meetings were also reviewed. Authors screened titles, abstracts, and full texts against predefined inclusion criteria: (1) studies addressing HCT in individuals with CF, (2) conducted in LMICs, and (3) reporting empirical data or descriptive program reports. Global and LMIC-Specific Evidence Findings:

Goals and Principles of HCT According to the definition from guidelines published by the Society of Adolescent Medicine, the goals of HCT are to improve the ability of youth and young adults to manage their own health care and effectively use health services, and to ensure an organized clinical process to facilitate transition preparation, transfer of care and integration into adult-centered care 8,9. The process should involve assessment of readiness, education, and preparation for transfer with careful coordination of transition care with an empathic intake.

Evidence from Middle and HICs CF literature from HICs underscore the benefits of structured CF transition programs, including improved adherence, better health outcomes, and enhanced self-management skills. Tools like CF R.I.S.E. and the Transition Readiness Assessment Questionnaire (TRAQ), which focuses on self-management skills, health system navigation, communication and advocacy, have proven useful in guiding transition readiness in the United States 10, 11. Both have been translated into many languages and utilized globally. In Türkiye, CF R.I.S.E. was successfully adapted and implemented, leading to positive feedback from participants 12. In Argentina, use of the TRAQ in HCT programs also correlated well with improved socioeconomic status, health coverage, education and condition-specific needs of adolescents 13. However, the TRAQ lends itself to HIC settings and is often contextually inappropriate in LMICs requiring adaptions 24,25. A recent review of transition programs in LMICs, based on literature prior to 2020, analyzed 10 studies involving over 1000 adolescents from Zimbabwe, Poland, Guatemala, Iran, Zambia, and Argentina 14. Studies involving Indian/Alaskan Native youth underscored the importance of holistic, culture-based understanding of adolescent values and morals to effective transition to adult care. In Zimbabwe and South Africa, a positive understanding of a disease process that was already stigmatizing in pediatrics and identifying peers and mentors with shared experiences allowed for less social isolation and better coping. Anecdotal observation of the impact of cultural and religious based norms was identified in South America and Southwest Asia, with the importance of religion to both caregivers and patients noted in Guatemala.

Evidence from LMICs Despite these efforts, few LMICs have operationalized structured, measurable HCT frameworks. Most LMICs rely on age cutoffs based on resource limitations and local societal norms, such as puberty and reproductive age, rather than readiness-based assessments (Table 1). In a review by Narla et al, the authors' analysis led to four overarching themes that include (1) clinical milestones, (2) adolescent-responsive health system change, (3) social and financial capital in transition, and (4) culturally sensitive measurement, evaluation and validation. As an example, the theme of clinical milestones included puberty as the trigger for transfer of care. While puberty is a celebrated time of cultural ascent to adulthood, centering HCT around this biological process was found to be detrimental to disease management both internally and externally as it does not address adolescent-specific needs.

Current evidence gaps identified Studies in LMICs, such as in Zambia, and Ethiopia, reveal major gaps in policy, provider training, psychosocial support, and family engagement 15-16. Recent reviews also highlight society level structural barriers, including poverty, gender inequities, and overall health system limitations as critical obstacles to successful transition 17. In Zimbabwe, transition barriers linked to poverty, gender and proximity of care only worsened entrenchment of these barriers. In the next section, we explore barriers to successful HTC in LMICs.

Implementation determinants (barriers) identified in HCT in LMICs Even in resource-abundant contexts, HCT is difficult to achieve; structural resource inequities further constrain its implementation in LMICs. In both HICs and LMICs, barriers to HCT emerge across levels – beginning with individual concerns such as developmental readiness or hesitation, extending to relational challenges such as fear of a new team or facility, and systemic gaps in continuity and care delivery 18. Beyond these shared barriers, pwCF in LMICs encounter further challenges that reflect broader social, economic, and health system constraints. Health system constraints include lack of adult CF programs, overburdened pediatric services, and limited access to multidisciplinary teams. Pediatric institutions need space and access to pediatric services, which often leads to earlier transition to adult care to accommodate these children. Adult institutions are often not designed with teams to address the complex medical and psychosocial needs of pwCF. Care models also may change from family-centered care to patient-centered care, requiring increased independence in self-care and decision-making from patients in a system fraught with structural obstacles, disability-based inequity, and lack of support around developmental readiness 19 (ref). While still poorly resourced in the pediatric setting, there remains an emphasis on the multidisciplinary team to the successful care of children with CF, including the physician, respiratory therapist, nurse, and dietitian. These multidisciplinary team members are more likely to be lacking in adult care. The presence of trained transition coordinators, psychologists, and social workers often improves outcomes by providing comprehensive support across medical, developmental, and psychosocial domains 29,30. Logistical and geographic limitations can often create transition urgency and thus dictate care teams, making it difficult for the patient or family to advocate for their adult care needs. Often within systems, resources are dictated by the developmental stage as well – for example, specific medications may be covered on the pediatric side, but not on the adult side. In the United States, eligibility thresholds for public insurance programs (e.g., Medicaid and Medicare) strongly influence models of care delivery, often superseding clinical judgment or patient–provider preferences. Additionally, proximity to academic or tertiary health centers where rare-disease care is available also can dictate care. Educational gaps become apparent from both a provider and CF community perspective. The lack of experience and knowledge may lead providers to make uninformed recommendations leading to avoidable outcomes and loss of trust. A lack of accessible information about CF as a chronic illness requiring lifelong care hampers advocacy by the healthcare community on behalf of pwCF. Stronger educational programs benefit resource-rich settings, including families of those with CF. As an example and despite being an upper-middle-income country (UMIC), programs like CF. R.I.S.E. have been instrumental in enhancing knowledge, disease management skills, and self-confidence among pwCF in Turkiye 12. Other barriers include disclosure of health information shaped by intersecting factors such as stigma, cultural norms around family-centered decision-making, and systemic resource constraints, which together can limit opportunities for independent decision-making and self-advocacy. A diagnosis of a life-limiting condition with associated disability can intersect with stigma, poverty, and health system barriers, making it harder for families to seek timely care and leading to worsening outcomes. As an example, in Jordan, the large number of caregivers and pwCF utilizing mental health resources underscores the need to confront mental health topics perceived as barriers. Pressure of implementing HCT early can coincide with increased mental health issues known to occur during adolescence. In cultures where mental health challenges are not widely discussed, patients may be under-treated, a known risk factor exacerbating the challenges of HCT.

Synthesis and discussion: Our review highlights the complex and multilayered barriers to HCT for pwCF in LMICs. To interpret these findings, we draw on a hybrid framework integrating the Social-Ecological Model (SEM) and the Social-Cultural Model (SCM). This lens recognizes that transition is shaped both by structural and systemic factors across ecological levels and by the cultural meanings, norms, and values that influence care. Below, we frame the discussion across levels of the model (Figure 1).

Individual level with cultural overlay: The importance of developmental readiness to transition, including cognitive and emotional maturity, needs to balance the resource limited settings that drive transition at a community and policy level. Gaps in knowledge about CF as a progressive illness that can be slowed by addressing self-managements skills can have a profound impact. It is also important to factor in the stigma and cultural beliefs around CF. The important societal significance of marriage and fertility among families may lead to 'hiding' the diagnosis of CF, or delayed disclosure. Chronic cough and malnutrition from CF can be misattributed to poor parenting or poverty, leading to delayed diagnosis and isolation, further impacting the transition to adult care. Adolescents in LMICs as young as 10 are transferred to adult care based on cultural definitions of maturity and the onset of puberty. In some LMIC contexts puberty is often regarded as the beginning of adulthood and often delayed. This perception leads to early transfer, regardless of emotional or cognitive readiness. Societal expectations may prompt adolescents to assume adult responsibilities early, such as caregiving or income generation, reinforcing the belief that they no longer require pediatric services. Gendered expectations around independence and modesty may accelerate movement of females with CF to female adult providers from male pediatricians.

Interpersonal, Family and Peer Level with Cultural Overlay: A globally recognized barrier enhanced in LMICs by lack of support for patient-centered care underscores difficulty accessing and advocating for care in adult settings at an earlier age. Cultural concepts such as family- and community-based collectivism can serve as important assets, with health responsibilities often shared across households and social networks31. These structures may strengthen caregiving, reduce isolation, and promote adherence by ensuring that adolescents are embedded in strong support systems. At the same time, expectations for adolescents to assume adult roles early—such as contributing economically, marrying, or caring for others—can shape how health systems and families perceive the need for adolescent-specific care. In some regions, family involvement and gendered norms may influence the degree of autonomy afforded to adolescents or limit access to reproductive health education. These dynamics may reflect deeply rooted cultural values that both support and complicate the developmental milestones of young pwCF, underscoring the need for transition approaches that build on familial strengths while also safeguarding adolescent-specific needs. During adolescence, developmental milestones such as increasing autonomy, identity formation, and peer relationships become especially important, making the role of families and peer networks central in the transition process. While this developmental trajectory is universal, the ways in which independence, maturity, and peer interaction are interpreted and supported vary across cultural contexts. For example, in Western contexts independence may be emphasized as a marker of readiness for transition, whereas in more collectivist contexts, family interdependence and shared decision-making may be seen as equally or more important to a successful transition. Religious and cultural beliefs may shape attitudes toward illness, independence, medical care, and responsibility in LMICs as well 21. For example, Catholic doctrine may influence views on reproductive and sexual health discussions 13. Indigenous belief systems may coexist with biomedical care and influence perceptions of chronic illness and transition needs 22. In Muslim-majority countries, Islamic teachings may guide family roles and influence disclosure timing. Spiritual frameworks often provide important sources of meaning, resilience, and coping for adolescents and families. At the same time, these frameworks may shape norms around communication, which can make open discussion of sensitive topics such as sexual and mental health less common. Recognizing both their supportive role and their influence on health-related dialogue is essential to developing transition approaches that are culturally congruent and responsive to adolescent needs. Transition programs in LMICs must engage spiritual, traditional and religious leaders and integrate holistic support to ensure culturally congruent care. These examples illustrate that cultural and spiritual influences on transition vary widely, both within and across countries, and that effective programs must engage community and religious leaders to ensure culturally congruent, adolescent-centered care.

Institutional/Health System Level: The lack of adult CF programs and experience underscores the institutional barrier to successful transition and further compounded by geographic and financial isolation. Many LMICs experience a demographic 'youth bulge,' with a substantially higher proportion of children and adolescents compared to HICs. This creates both challenges and opportunities for health systems, particularly in planning for chronic disease management and transitions of care. Delayed transition of young adults with CF strains pediatric systems, limits bed availability, and risks diminishing care quality for younger patients. However, without transitional care support and an individualized and holistic approach to pwCF, transitioning to adult care, medical and psychosocial care is compromised despite the argument for greater autonomy. This notion does not consider the stages of adolescent growth that continues to at least 18 and beyond. Limited resources also constrain implementation of multidisciplinary care and team-based approach to clinical care. Gender segregation associated with puberty and limiting care to gender based providers may restrict access to local experts32. The socio-cultural model highlights the institutional bias which leans towards acute management with less focus on the clinical and psychosocial needs of adolescents and young adults. Emphasis of CF R.I.S.E. in Turkiye is an example of adapting institutional programs to culture.

Community/Societal Level: Weak or absent community education programs on CF can hamper the efforts of both pediatric and adult services, but most importantly for adolescents who benefit from exposure to age related best practices as well as anticipatory guidance as they enter adulthood. Overemphasis, earmarked funding, or vertical programming, for example sexual and reproductive health (SRH) care, may prevent additional necessary subject from being covered 27. Transportation needs to access healthcare can be confounded by poverty and an inability to overcome financial barriers. Though many LMIC countries offer universal healthcare, expert CF care may not be available at the public institutions. Stigma around CF further reinforces silence at the community level which can result in withdrawal from society. Local religious and cultural practices can also shape attitudes toward care and disclosure. Adolescents may be considered 'unsuitable' for marriage due to infertility or chronic illness, further stigmatizing pwCF in their communities. Mental health stigma is perceived to be strong and can enhance the stress associated with transition but anecdotal evidence in Jordan and other areas suggest the need greatly outweighs the risk. Also, adolescents with CF moving into adult care may face dismissive providers or lack of services if their appearance belies the urgency, reinforcing the sense that their disease is invisible.

Policy/Legal Level: Privacy concerns and protections for adolescents, whether in a pediatric or adult setting, can jeopardize willingness of pwCF to disclose and advocate for themselves. Robust privacy protections are generally lacking in LMICs, including many in the Southwest Asia, Northern Africa, and parts of Asia and Latin America 20. Anecdotally, countries like Nigeria, Philippines, South Africa have constitutional or statutory frameworks protecting privacy according to anecdotal information. Most developed countries allow minors to consent to certain healthcare independently from parents, but this is not universally established in many parts of the globe (WHO data). To put this in context, state sponsored voting is consistently 18 in LMICs across continents, with exceptions like Ethiopia which allow 16-year-olds to vote. Military service is compulsory in many LMICs at age 18 and as young as 16 with parental consent. However, access to sensitive medical care may not mirror these other legal rights (ref)

Conclusion: The transition from pediatric to adult CF care in LMICs is not only a medical necessity but a moral imperative to reduce disparities and optimize health systems. Recognizing the complex interplay of resource constraints, cultural beliefs, and systemic limitations is essential to crafting effective, humane and sustainable transition programs. Global CF partnerships must support LMICs in building adolescent and young adult centered models that reflect local values and realities.

Recommendations Develop region-specific transition policies using contextually derived and validated tools adapted for language, education and literacy levels. Train providers in adolescent-responsive care, including reproductive and mental health counseling. Engage families and communities, including community, traditional, spiritual and religious leaders, in shared decision-making. Strengthen pediatric care as a model for adult multidisciplinary care of adults transitioning to adult care Extend transition support in rural or under-resourced areas to address proximity of care as a barrier to transitional care support, including telehealth. Employ human-centered design and participatory research methods that elevate adolescent voices, ensuring culturally appropriate, sustainable models that balance youth autonomy with family and community engagement Initiate or improve newborn screening and diagnostic resources that fit the population needs, to increase awareness and determine prevalence with goal of appropriate allocation of resources from the ministries of health providing access to mental health support and finding ways to link stigmatizing conversations to supporting health

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Table 1. Average Age for Healthcare Transition by Country or Region

Country/Region	Recommended age (or range) to transfer from pediatric to adult CF care
United States (HIC)	18–21 years
Canada (HIC)	Late adolescence ([?]18–19 years)
United Kingdom (HIC)	Around 16–18 years
France (HIC)	Late adolescence ([?]18 years)
Germany (HIC)	Late adolescence ([?]18 years)
Australia (HIC)	Late adolescence ([?]18 years)
New Zealand (UIC)	Late adolescence ([?]18 years)
Brazil (UMIC)	Late adolescence ([?]18–19 years)
South Africa (UMIC)	Late adolescence (often [?]18 years, where services exist)
India (LMIC)	Variable; often delayed beyond 18 years
Israel (HIC)	Late adolescence ([?]18 years)
Turkiye (UMIC)	Late adolescence ([?]18 years)
Japan (HIC, low CF prevalence)	Case-by-case in late adolescence
Europe (overall and includes some LMICs)	18 years common; some early 20s
Global LMICs (general)	Often 18 years, frequently variable/delayed and inpatient earlier at around age

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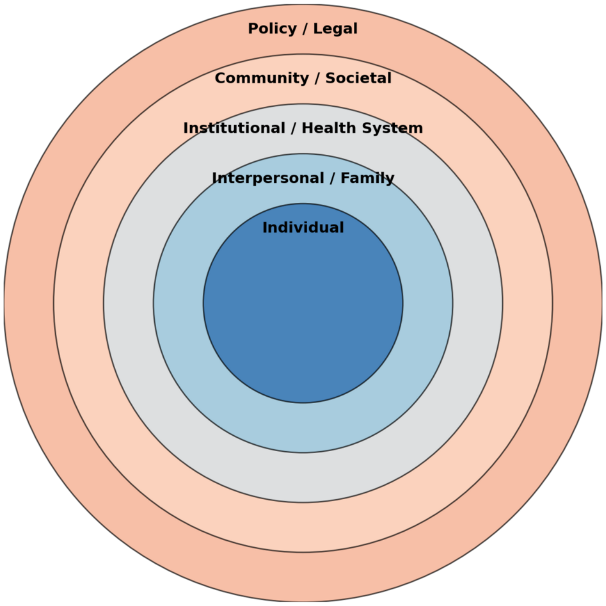
Figure 1. Hybrid socio-ecological and socio-cultural framework for healthcare transition barriers and facilitators impacting people with cystic fibrosis in low-middle income countries.

Hybrid Socio-Ecological & Socio-Cultural Framework
Transition from Pediatric to Adult Healthcare in LMICs



Individual:
Beliefs about illness, stigma,
resilience assets, gender roles

Interpersonal / Family:
Family decision-making,
collectivism, caregiving norms

Institutional / Health System:
Multidisciplinary gaps,
resource constraints,
gender segregation

Community / Societal:
Stigma, religious/cultural norms,
indigenous practices, peer groups

Policy / Legal:
Definitions of adulthood,
consent, funding priorities

Hybrid Framework for Transition in LMICs:
- Socio-Ecological Model (circles) → structural layers of influence
- Socio-Cultural Insights (side text) → norms, values, stigma, collectivism

Together, they illustrate how systemic and cultural factors shape adolescent transition from pediatric to adult healthcare.