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Paediatric to adult healthcare transition in resource-limited settings: a narrative review

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ABSTRACT

Background Ageing into adulthood is challenging at baseline, and doing so with a chronic disease can add increased stress and vulnerability. Worldwide, a substantial care gap exists as children transition from care in a paediatric to adult setting. There is no current consensus on safe and equitable healthcare transition (HCT) for patients with chronic disease in resource-denied settings. Much of the existing literature is specific to HIV care. The objective of this narrative review was to summarise current literature related to adolescent HCT not associated with HIV, in low-income and middle-income countries (LMICs) and other resource-denied settings, in order to inform equitable health policy strategies.

Methods A literature search was performed using defined search terms in PubMed and Cumulative Index to Nursing and Allied Health Literature databases to identify all peer-reviewed studies published until January 2020, pertaining to paediatric to adult HCT for adolescents and young adults with chronic disease in resource-denied settings. Following deduplication, 1111 studies were screened and reviewed by two independent reviewers, of which 10 studies met the inclusion criteria. Resulting studies were included in thematic analysis and narrative synthesis.

Results Twelve subthemes emerged, leading to recommendations which support equitable and age-appropriate adolescent care. Recommendations include (1) improvement of community health education and resilience tools for puberty, reproductive health and mental health comorbidities; (2) strengthening of health systems to create individualised adolescent-responsive policy; (3) incorporation of social and financial resources in the healthcare setting; and (4) formalisation of institution-wide procedures to address community-identified barriers to successful transition.

Conclusion Limitations of existing evidence relate to the paucity of formal policy for paediatric to adult transition in LMICs for patients with childhood-onset conditions, in the absence of a diagnosis of HIV. With a rise in successful treatments for paediatric-onset chronic disease, adolescent health and transition programmes are needed to guide effective health policy and risk reduction for adolescents in resource-denied settings.

What is known about the subject?

- Healthcare transition (HCT) is a complex process that requires intentional planning and institutional buy-in.
- Adolescent healthcare needs to be adolescent responsive and to promote ownership of their own care.
- Structural barriers are a critical limitation to achieving health equity.

What this study adds?

- There is limited published literature and available data on HCT in resource-limited settings, despite a growing need.
- In resource-denied settings, there are many structural barriers that impede achievement of equitable HCT and adolescent care.
- Mental health and social and financial capital appear critical in supporting safe transitions of care for adolescents living with chronic disease, especially in resource-denied settings.

INTRODUCTION

Adolescence is a complex developmental period; those with chronic diseases are at an even higher risk during this time, with unique vulnerabilities, health concerns and barriers to care.[1] Evidence exists that poorly managed transition of paediatric to adult care can be associated with increased risks of treatment failure, loss to follow-up, and subsequent increase in morbidity and mortality.[2 3] Many high-income countries have implemented the concept of healthcare transition (HCT), defined as the process of moving from a paediatric-centred to an integrated adult medical home, into their clinical services.[4–7] Yet, a notable care gap for adolescents continues to exist worldwide,[8] complicated by minimal data on HCT in resource-limited settings.

The majority of summarised literature to date related to adolescent HCT in a global context is solely focused on HIV. Over the past decade, as the total number of adolescents living with HIV increased nearly

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threefold primarily in sub-Saharan Africa, more attention was devoted to understanding the importance of HCT to adolescent HIV outcomes in low-income and middle-income countries (LMICs).[9] Important insights were discovered regarding the barriers and facilitators associated with successful implementation in more resource-limited contexts, but with substantial variation across country-specific guidelines.[10] In a recent systematic review summarising literature related to HCT for adolescents living with HIV in LMICs, Jones *et al* concluded that surveillance systems to monitor and evaluate needs during transition, incorporation of caregiver and adult treatment team training, and development of specific HCT guidelines may better facilitate successful transition for adolescents living with HIV.[10] Given the inequity that often exists across other less-funded disease burdens, the purpose of this study was to review available literature on paediatric to adult transition and age-appropriate care of adolescents with paediatric-onset disease in the absence of a diagnosis of HIV and in limited resource settings, in order to inform strategies for transition across varied resource settings.

METHODS

Inclusion criteria

Reviewers sought both qualitative and quantitative studies assessing factors that influence adolescent healthcare, specifically paediatric to adult transition, where resources are scarce. Articles published before January 2020 that met all of the following criteria were included (1) those conducted in a resource-denied setting, as defined to include population subsets limited by proximity, care access, geographical diversity and calibre of health system in delivering standard of care; (2) those with adolescents and young adults (AYAs) with either a chronic disease, psychosocial vulnerability or both; and (3) those published in a peer-reviewed journal. We defined psychosocial vulnerability as the presence of increased mental, emotional, financial or social risk factors that are shown to impact good health.

Search strategy

Both PubMed and the Cumulative Index to Nursing and Allied Health Literature databases were searched using a comprehensive search strategy that combined both keywords and controlled vocabulary terms, consisting of the appropriate Medical Subject Headings, from each database. No lower date or language restriction was specified. The search strategy identified articles that paired keywords and controlled vocabulary terms relating to the concepts of adolescence, continuity of care or transition of care and LMICs. All keywords and phrases were searched in both the title and abstract in order to ensure relevancy of the results; however, keywords were expanded to the fullest capacity necessary to ensure sensitive return from the databases. The strategy actively excluded paediatric developmental stages other than adolescence. The strategy also excluded HIV and various keywords associated with HIV. A full copy of the search strategy can be obtained in the supplementary data or by contacting the authors (see online supplemental 1).

Searches in both databases were run on the same day in January 2020. Resulting citations were deduplicated in EndNote using the deduplication method outlined in Bramer *et al*[11] and then imported into Covidence reviewing software for screening.

Data extraction/analysis

After removing duplicates, abstracts from the initial search results were screened by the two primary study authors to remove articles that did not meet the study inclusion criteria. The search yielded abstracts in English for initial screening; however, original manuscripts were in a diversity of languages. An independent second round of screening with full-text review for eligibility was then performed by study evaluators using a standardised extraction table. All discrepancies were discussed until consensus agreement was reached. If the described study population was resource-denied with regard to surrounding health systems context (ie, the Indian Health Service and tribal health in the USA has significantly fewer resources and capabilities than other health systems in similar areas), reviewers opted to still include in the study despite country classification by aggregate World Bank indexing.

Articles were categorised by target population demographics, country, study design, aims, disease burden evaluated, and any health system barriers referenced. Given the significant heterogeneity in study designs, methods and outcomes captured, a cross-study comparison was not felt to have meaningful application and requisite criteria for formal meta-analyses were not met. Rather, themes and subthemes related to identified challenges and mitigating factors for successful HCT were extracted using an inductive analysis approach.[12] Initial themes were identified based on prominent findings, study discussions and identified implications. Independent coding of all included studies was performed using Microsoft Word by two reviewers (NPN and LR), without requirement of qualitative analytical software. Coding differences were verbally resolved for consensus agreement, with examples of supporting text and references to associated manuscripts arranged into tables of themes and subthemes. Further comparison led to refinement of themes, prior to narrative synthesis of the emergent themes. Due to the heterogeneity and limited number of studies, saturation was not achieved.

RESULTS

Figure 1 presents the Preferred Reporting Items for Systematic Reviews and Meta-Analyses flowchart breakdown from results of the search strategy and data extraction. The initial search resulted in 1429 citations. Following deduplication, 1111 abstracts were screened by

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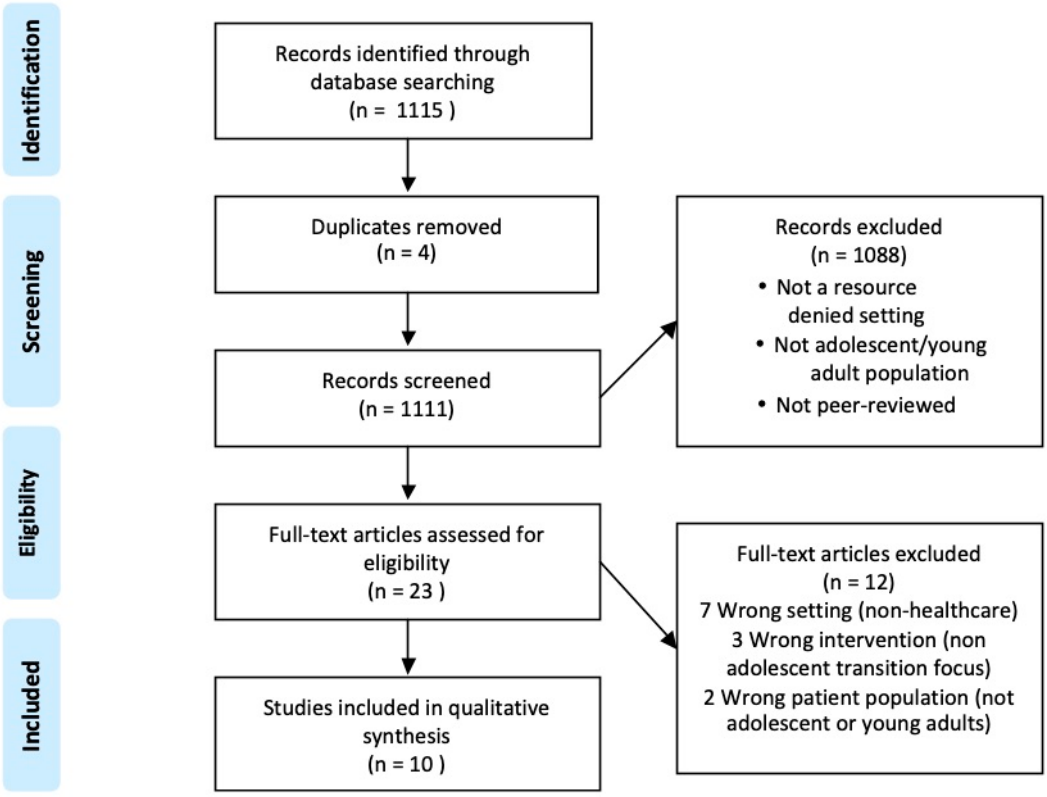

Figure 1 Article selection flowchart.

two independent reviewers. Ten studies were ultimately included for full-text review by content experts, and themes were independently extracted.

Study characteristics and participants

Over 1000 adolescents, including parents and key stakeholders involved in providing health services, were included in the eligible studies (table 1). Studies were conducted in varied geographical locations in North and South America, Europe, Africa and Asia, including Zimbabwe, Poland, Guatemala, South Africa, Iran, Zambia, Argentina, Alaska and Brazil. Types of studies included cross-sectional surveys with mixed-methods analysis (n=3), key informant interviews with qualitative analysis (n=4), randomised controlled trial (RCT) (n=1) and context-specific commentary reviews (n=2). Studies were conducted with adolescents from diverse disease streams, including autism, cerebral palsy, muscular dystrophy, epilepsy, cancer, lupus, juvenile idiopathic arthritis and other psychosocial vulnerabilities, including lack of parents and poverty. Structural barriers, or obstacles that impact one group of people disproportionately to promote cyclical inequity, were consistently referenced in 8 of the 10 studies.

Emergent themes for adolescent care transition

Analysis led to 12 emergent subthemes, which were clustered into four overarching themes (table 2). These are discussed below.

Clinical milestones

Several studies identified the importance of puberty and reproductive health as a timely developmental milestone in determining transition readiness.[13–15] Difficulty talking to adolescents about puberty, societal pressures, as well as gender inequity led to cyclical structural barriers. Azh *et al* elucidated how lack of knowledge, comfort, or cultural barriers in discussing reproductive health can promote unfavourable health-seeking behaviour.[13] In fact, education for milestones such as puberty, sexual health, nutrition and life skills, including healthy relationships, was identified using an asset-based theory of change in Zambia, for implementation in a large RCT.[16]

While puberty is considered the appropriate age for transition in many contexts, adolescent transition may require an individualised timeline. For example, in South Africa, abrupt transfer or referral at age 13 years was felt to be detrimental to disease management. Recruiting one member of the paediatric team to become educated in adolescent-specific needs was felt to be useful for facilitating transition.[17]

Adolescent-responsive health system change

Several studies illustrated the importance of system adaptation to support the unique needs of young adults with chronic disease. In Brazil, however, the health system overall was noted to be ill-equipped to support confidentiality, autonomy and skill navigation.[18] Structural barriers to health system change, including poverty,

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Table 1 Summary of studies identifying needs of adolescents and young adults with chronic diseases*

Authors (year)	Context/study design/area of resource scarcity	Aims	Description/demographics	Comments and findings related to disease burden and structural barriers	Study limitations
Study 1 Platos and Pisula[20] (2019)	▶ Poland, population subset with ≥1 reported barriers to service use. ▶ Cross-sectional survey study of adolescents with ASD. ▶ Secondary analysis of service use from nationwide Polish Autism Survey using convenience sampling and parental informants.	To evaluate 1. Services used by patients with ASD and predisposing factors for use. 2. Unmet needs for services and factors that prevent use. 3. Barriers to services and who is at greatest risk of facing these.	▶ n=311. ▶ Race/ethnicity: not reported. ▶ Median age: 16.6 years (12–39) ▶ Sex: 79% male. ▶ Comorbidities: 45% Intellctual Disability, 58% psychiatric/ mental health. ▶ Socio-economic status: 21% poorest quintile, 36% from large city.	Childhood autism, atypical autism, Asperger syndrome Structural barriers included household income, female gender and rural location. Examples: people with higher income had fewer unmet needs for sensory/ motor services (p=0.018), and women had more unmet needs than men (p=0.04); services were reported too costly more often with younger age (12–14 years), low household income and attending an integrated classroom; unavailable services were associated with living in a village and medium/small city.	▶ Convenience sampling limits result generalisability, and study population may over-represent those living in larger cities. ▶ Patients who did not use any services were likely underestimated, as surveys were distributed through service providers. ▶ Self-reported study. ▶ Relied on parents as informants.
Study 2 Mhongera and Lombard[19] (2016)	▶ Zimbabwe. ▶ Qualitative analysis of key-informant interviews with orphan adolescent girls and superintendents on transition services. ▶ Sustainable livelihood approach, purposive sampling.	To evaluate effectiveness of institutional transition programmes in promoting sustainable livelihoods by assessing 1. Livelihood needs of orphan adolescent girls. 2. Governmental services to meet identified needs and adolescent-perceived adequacy of support.	▶ n=32. ▶ Sex: all female. ▶ Age: 15–18 years (with understanding of transition issues, not yet exited institutional care) and 18–21 years (discharged from care within a 3-year period).	No specific disease burden, but psychosocial vulnerabilities included no parental figures. Examples of structural barriers: ▶ No institutional financial assets provided for adolescent girls inside care. ▶ No access to training programmes to enhance capacity for independent living. ▶ Significant financial insecurity post-transition make them vulnerable to homelessness and abuse. ▶ No tap water or latrines in many villages, have to fetch water from river. ▶ Lack of access to transport services results in social exclusion and isolation, particularly in rural areas.	▶ Lack of effective case management made it difficult to locate adolescent girls who had transitioned from institutional care. ▶ Small sample size.
Study 3 Saetermoe *et al*[22] (2004)	▶ Guatemala. ▶ In-depth interviews of caregivers for adolescents with severe childhood-onset disabilities, analysed using constructivist grounded theory† framework.	To examine 1. The role of tangible resources in influencing economic/social outcomes of adolescents with disabilities. 2. Factors optimising their developmental progress and social adjustment. 3. Resources available and still needed.	▶ n=15. ▶ Patient median age: 15.6 (age: 12–20 years). ▶ Sex: 53% female. ▶ All with non-traumatic chronic/ debilitating condition for ≥12 months. ▶ Spanish-speaking, born in Guatemala. ▶ Primarily urban dwelling, somewhat more advantaged than the general population.	Cerebral palsy (53%), muscular dystrophy (13%), polio (13%), spina bifida (6.6%), cleft palate (6.6%), Guillain-Barré syndrome (6.6%) ▶ None had medical insurance. ▶ If caretaker had financial urgency, their primary goal was to help adolescent become economically independent, and financial independence often becomes a priority over healthcare. ▶ Poverty associated with unacceptable levels of healthcare.	▶ Exploratory study with small sample size.

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Table 1 Continued

Authors (year)	Context/study design/area of resource scarcity	Aims	Description/demographics	Comments and findings related to disease burden and structural barriers	Study limitations
Study 4 Stefan[17] (2008)	▶ South Africa. ▶ Review article with context-specific commentary on mandatory age 13 transition care for adolescents with cancer.	To describe specific needs of adolescents with cancer for broader implications in the developing world	▶ Age: 10–19 years.	Diseases included range of childhood-onset cancers and related psychosocial needs.	▶ Descriptive review without detailed or rigorous methodology outlined. ▶ Limited to cancer-specific literature.
Study 5 Azh *et al*[13] (2017)	▶ Tehran, Iran. ▶ Qualitative analysis of in-depth interviews (n=30) and group discussions (n=9) using grounded theory.	To explain perception of adolescent youth and stakeholders to improve health programmes for safe transition	▶ n=67 adolescents (age: 14–18 years), 8 youths (age: 19–24 years), 12 additional parents/healthcare provider stakeholders. ▶ Sex: 67% female (62 female, 30 male). ▶ Conducted in boys' and girls' schools, universities, municipality culture centres.	No specific disease burden; adolescent perspective related to confusion in receiving health services, policy-related to providing comprehensive health services, optimising influential factors, and empowering adolescents, specifically surrounding puberty	▶ Limited to one city in Tehran, less generalisable ▶ Relatively small n with no specific disease burden
Study 6a (protocol)* Hewett *et al*[16] (2017)	▶ Zambia ▶ Multi-arm randomised control trial -protocol to assess interventions for adolescent girls in LMICs	To assess impact across long-term outcomes, including: early marriage, first birth, contraceptive use, educational attainment, and HIV (acquisition) following programme completion, and after 2 years of follow-up	▶ n=10 000 girls (age: 10–19 years) targeted by intervention (AGEP) across sites (one-half urban and one-half rural) in four provinces, specifically designed to reach most vulnerable. ▶ Three randomisation intervention arms and one control arm. ▶ Intervention arm 1 : weekly girls group mentor-led session (curricula).Intervention arm 2: curricula+health voucher. ▶ Intervention arm 3: curricula +health voucher +bank account	No specific disease burden, this study looks at unique adolescent and young adult 'vulnerabilities' influencing reproductive health and poverty-driven disease. Structural barriers included poverty, poor access to banks, poor access to healthcare, financial insecurity as well as cultural pressures creating vulnerabilities around safe partnerships.	▶ Relatively large study with large intervention that could be hard to replicate (and maintain) when resources are scarce.
Study 6b (study)* Austrian *et al*[14] (2020)	▶ Zambia. ▶ Cluster randomised controlled trial with longitudinal interval follow-up.	To conduct an intention to treat analysis to assess intervention impact (on social, health and economic assets, sexual behaviours, education and fertility outcomes).	▶ Never married adolescent girls (n=3515 girls in intervention clusters and 1146 in control clusters) ▶ Evaluated at baseline and 2 and 4 years postintervention	This study showed lack of hypothesised change overall, though there were significant results in short-term outcomes. (This intervention did not lead to participants increasing broad-reaching changes in social and structural determinants.)	▶ No significant results despite the rigour of this study.
Study 7 González *et al*[23] (2017)	▶ Argentina. ▶ Validation of TRAQ (in Spanish) 5.0. ▶ Descriptive/cross-sectional study with quantitative methods.	To validate transition readiness assessment questionnaire in Spanish	n=191, 96.3% understood and completed correctly. Age: 14+ years treated at Hospital Garrahan.	Chronic health conditions, assessed 'Unmet Basic Needs Index', which is a measure of structural poverty, but does not explain details of how that impacted validation	▶ Does not address the structural barriers to transition that the TRAQ does not assess.

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Table 1 Continued

Authors (year)	Context/study design/area of resource scarcity	Aims	Description/demographics	Comments and findings related to disease burden and structural barriers	Study limitations
Study 8 Friesen *et al*[21] (2015)	▶ Alaska (AI/AN population). ▶ Review of three qualitative studies using 'relational worldview framework' qualitative analysis.	To evaluate collective versus individualistic culture and its impact on youth and healthcare.	▶ AI/AN youth ▶ Conducted at a community based agency that provides services to self-identified AI/AN youth and young adults and their families in a three-county area	No particular disease burden Collective culture influences development and transition; therefore, the system needs to reflect these crucial developmental needs. Structural barriers were systemic structures that were based on individual cultural assumptions, rather than a collectivist culture to support developmental maturity and health-seeking behaviour.	▶ Relational world view framework is difficult to use in other contexts. ▶ Difficult to blend cultures and practices in bigger systems.
Study 9 Azh *et al*[15] (2017)	▶ Tehran, Iran. ▶ School-based interviews. ▶ Analysed with grounded theory. ▶ Purposeful sampling with maximum diversity approach.	To explain adolescent and key informant perception of healthcare provision	n=65 adolescents, 9 youths (19–24 year olds), and 19 parents and key stakeholders involved in providing health services in 9 group discussions and 30 individual interviews	Otherwise healthy, discussion around puberty ▶ Disrespect for adolescent's rights. ▶ Cultural and societal pressures. ▶ Inadequate information/lack of virtual platforms.	▶ Some limitations due to specifically cultural implications in Tehran, limiting generalisability. ▶ The focus of this study on adolescents with no specific medical condition may have limited application to chronic paediatric-onset disease.
Study 10 Anelli *et al*[18] (2017)	▶ Brazil. ▶ Surveyed paediatric rheumatologists, which was culturally adapted from Childhood Arthritis Rheumatology Research Alliance (USA and Canada).	To better understand transition practices, including tools and best practices in rheumatology in Brazil	n=112 paediatric rheumatologists, 76 responded to survey ▶ 13% reported that they had a well-established programme, and 14% reported being satisfied with their transition process. ▶ 80% did not use any specific process.	Rheumatological disease: Systemic lupus erythematosus, Juvenile idiopathic arthritis, Juvenile rheumatoid arthritis, Brazilian health system setup with poor infrastructure for 'non-emergent' planning This study was done in academic centres where technology was available for communication but not generalisable, given lack of email/text available country-wide.	Results are remarkably congruent with Canadian results, suggesting issues are global, though authors note some of the financial pressures and unique decentralisation of Brazilian health system may deprioritise transition, and therefore skew the results

*Protocol was included given relevance; full study was published in March 2020 and was reviewed in context (see study 6b).
†Adapted from Charmaz.[30]
AGEP, adolescent girls Empowerment programme; AGEP, Adolescent Girls Empowerment Program; AI/AN, American Indian/Alaska Native; ASD, autism spectrum disorder; SES, socioeconomic status; TRAQ, Transition Readiness Assessment Questionnaire.

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Table 2 Global themes with 12 subthemes

Overarching theme	Subthemes	Recommendations
Clinical milestones	1. Puberty, reproductive health (studies 9, 6 and 5). 2. Individualised transition timing (studies 4 and 10).	HCT should be timed based on reaching appropriate clinical milestones from both the provider and patient perspectives, including physiological changes such as puberty, but also other clinical milestones including understanding of one's disease.
Adolescent-Responsive Health System Chang	3. Community adolescent-responsive health system (studies 2, 5 and 8). 4. Transition timing (studies 4 and 10). 5. Proximity to care (study 6). 6. Poverty driven obstacles (studies 1, 2, 6 and 8). 7. Need for health system strengthening, with unmet services (studies 1, 6 and 5).	Successful HCT must address multiple structural barriers that adolescents have to care, including proximity to healthcare facilities, disparity in policy and funding in care, stigma, tribalism and racism.
Social and financial capital in transition	8. Resilience tools and education (studies 2, 3, 5 and 10). 9. Peer support (study 4). 10. Mental health comorbidity (study 1). 11. Financial empowerment and employment (studies 2, 3, 6 and 8).	Successful HCT should have a holistic approach and should build social and emotional support, as well as address financial empowerment to aid adolescents in becoming self-sufficient.
Culturally sensitive measurement, evaluation and validation	12. Language validation of surveys (study 7). 13. Measurement and evaluation of programme implementation (study 6).	In resource-denied settings, particularly with culturally and linguistically diverse patient populations, equitable approaches to data collection and analysis are necessary to capture all perspectives of vulnerable groups. Specific considerations to maximise diversity in sampling approaches, and the use of evaluation frameworks that allow for flexible exploration of context-specific nuances are important. More non-English language survey validation and rigorous RCTs are needed in LMICs, despite successful precedents.

HCT, healthcare transition; LMICs, low-income and middle-income countries; RCT, randomised controlled trial.

gender norms and proximity to care, were frequently cited. Qualitative analysis from adolescent interviews in Zimbabwe showed that lack of access to transport services for adolescents resulted in social isolation, particularly in rural areas. Ineffective transition care appeared to increase adolescent girls' vulnerability to poverty and gender inequality.[19] In a Polish survey of young adults with autism spectrum disorder, high cost and unavailability were the most frequently reported barriers to services.[20] In Zambia, when the studied intervention did not show widespread impact on the cultural norms that lead to adolescent vulnerability, the authors hypothesised that one limitation to sustained programmatic success was the need for more tailored interventions based on individual and community needs.[16]

Partnering with adolescents to identify their needs for system change can be a valuable strategy. Anelli *et al* noted that the Brazilian rheumatologists had many similar hurdles as those in the USA and Canada for effective transition; there was a lack of adolescent-specific programming, resulting in poor provider and patient satisfaction with the process.[18] In one study of an American Indian/Alaska Native youth cohort, a relational worldview framework was used to demonstrate well-being as a balance among the domains of mind, body, spirit and context.[21] A holistic understanding of adolescent values, morals, self-identified culture and perceptions of health was found to be crucial in effective system design.[21]

Social and financial capital in transition

Social resources to optimise during the transition process, including resilience and education tools, peer support, mental health support and financial empowerment, were frequently referenced. For orphan adolescents

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in Zimbabwe, authors note a need for positive youth development programmes for mentoring and social networking. They found that provision of services and support to create pathways of access for basic livelihood needs and long-term survival were most valued.[16]

Effort was required early to overcome uneasiness of transition, establish rapport with new providers and develop trust for adolescent patients with chronic disease. Stigma associated with their disease process can create feelings of isolation, which may be mitigated by accessing social capital through shared experiences with peers. In adolescents with cancer in South Africa, creating separate wards for adolescents was felt to help with shared experience and coping.[17] Mental health services, including group therapy, were the most used and most needed for adolescents with ASD in Poland.[20] Importantly, religion appeared an important motivator for both caretakers and patients in Guatemala and may play a role in facilitating resilience during adolescence in similar resource-denied settings.[22]

Finally, financial empowerment was noted to be a key factor in an adolescent's capital for successful transition to adulthood. Interviews with orphan adolescent girls in Zimbabwe on transition services indicate that financial capital is the most versatile category of assets. Significant financial insecurity post-transition made them vulnerable to experiencing homelessness and abuse.[19] Interviews of caregivers for adolescents with childhood-onset neurological conditions in Guatemala revealed that targeted transition care is more effective when understanding the impact of disability on economic resources.[22] When families had greater resources, more long-term emphasis on educational and professional development of the adolescents were exhibited. Similarly, in Alaska, widespread oppression was noted as a culprit to poor health.[21] In Zimbabwe, providing young adolescent girls with bank accounts and curriculum on financial empowerment appeared to be key in perceived improvement in health and quality of life.[19]

Culturally sensitive measurement, evaluation and validation

An important consideration in this review, with a majority of non-English-speaking patients, was methodological assessment, including language validation of surveys used and culturally sensitive measurement of programme implementation. Successful qualitative methodology approaches for equitable data collection and analysis included sustainable livelihood approach,[20] purposeful sampling with maximum diversity approach,[13 20] constructivist grounded theory framework[22] and relational worldview framework.[21]

In Argentina, González *et al* used a descriptive, cross-sectional, quantitative measure to successfully validate a widely used self-measurement tool to help guide transition needs: the Transition Readiness Assessment Questionnaire (TRAQ) V.5.0 in Spanish (n=191, 96.3% understood and completed correctly).[23 24] Discrimination by socioeconomic status, health coverage, education and condition-specific follow-up was independently evaluated, and the Unmet Basic Needs Index was used to help identify if structural barriers would discriminate validation. TRAQ V.5.0 in Spanish showed good correlation in results.[23] Hewett *et al* demonstrated novelty in the rigour of a large RCT context-specifc intervention in Zambia, tailored to evaluate effectiveness of age-appropriate longitudinal support and the impact on behaviour change for vulnerable adolescent girls.[16]

DISCUSSION

Timing, resources and considerations for equitable HCT should address the structural obstacles that youth face globally. Programme and policy for equitable HCT in these settings should consider (1) clinical milestones, (2) healthcare access, (3) social and financial capital, and (4) culturally sensitive measurement and evaluation. The identified studies provide a window into the complexity required to support context-driven, culturally adapted, effective transition policy in resource-denied settings. Crucial implementation research is needed to better measure how barriers such as racial oppression, poverty, gender discrimination and disability can be addressed in AYA policy and practice. While HIV has paved the way for this work, there remains a tremendous care gap for adolescents living with chronic illness in LMICs. Evidence from this review highlights resource mismatch, lack of age-appropriate healthcare, and limited opportunities for self-empowerment as persistent barriers to HCT. This review aimed to call attention to the importance of intentionally addressing structural violence as the root cause for failed transition. This can be mitigated if programme design is done with input from economically, racially and gender-diverse patient populations. Recognising that those with more marginalised identities will have a harder time accessing and participating in their care is critical when designing HCT programmes and policy.

Based on this review, we summarise the following recommendations.

Timing of transition to adult care not only should include physiological changes such as reaching puberty but also should address holistic clinical milestones

Due to a myriad of factors, transfer of care in resource-denied settings often occurs around puberty, with adolescent care centring solely around reproductive health. The narrow view of transfer at puberty neglects the natural heterogeneity of emotional and intellectual maturity required to self-navigate and self-advocate for one's own healthcare at that age. If transition occurs prior to individual readiness, especially in the setting of resource-related care gaps, there is an increased risk of failure. Transition must be defined by a holistic approach to well-being rather than a myopic view of physiological milestones. This recommendation is additive to current HIV transition literature. In a large systematic review for HCT in adolescents with HIV in LMICs, promising programmes

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were found to be patient-centred, to encourage early discussions about HCT for adolescents living with HIV and to maintain flexibility to delay transition if the necessary skills to manage care had not yet been developed.[10]

Access to healthcare and health system reforms must be addressed in order to provide equitable transition

In resource-rich settings such as the USA, six core elements, as outlined by gotransition.org,[25] have largely set the foundation for HCT through quality improvement methodology.[26] Though quality improvement allows for local adaptation, it does not address equity with intentionality. Similarly, in well-funded, non-orphan disease streams where care is no longer as cost-prohibitive, addressing inequity in transition is not usually deliberate. Thus, this is often missing in the current HCT literature for HIV in LMICs.[27] It is not enough to create programming around adolescent empowerment if the structural systems in which they are living remain prohibitive to sustained success.

Adolescent-responsive HCT requires optimising social and financial capital

The WHO is urging countries to move from 'adolescent-friendly' services to 'adolescent-responsive' policy.[28] This review illustrates that operationalising policy in a way that represents the collective voice of adolescents remains difficult. Policy needs to include representative voice to better understand structural elements that are preventing developmentally appropriate care into young adulthood and impeding safety to the adult world. Prominent themes in this review include enhanced mental health and social and financial capital to support this new appropriate level of independence and to overcome cyclical poverty.

Some of these findings are in line with prior large-scale studies examining transition for adolescent patients with HIV in LMICs, including social peer support, skills development, multidisciplinary treatment teams, and active patient–provider communication regarding the transition process.[7 10 28 29] However, there is limited empirical evidence provided on factors perpetuating sustained incorporation of HCT concepts within the population for disease streams with less vertical funding. A range of adolescent perspectives is required to address context-driven barriers for successful HCT. Because different diseases result in different impairments, this is best supported by a multidisciplinary cross-sector approach. Implementation needs to continue to address the 'why' of exclusion, through the upstream creation of these disparities.

Culturally sensitive measurement, evaluation and validation are necessary to create an evidence base for effective transition policy

This review demonstrates examples of various sampling approaches and evaluation frameworks that allow for flexible exploration of nuances. Instruments that have been validated in a resource-rich context are not necessarily accurate in other contexts, particularly with culturally and linguistically diverse patient populations. With a limited number of precedents, more non-English language survey validation and rigorous RCTs are needed in LMICs. Tools should be made with intentional inclusivity so that resultant policy and programmes are created to preferentially support those at the periphery.

Limitations

The limitations of this study are mainly around the dearth of published knowledge in this area, with challenges in standardising analysis for the few relevant and extremely heterogeneous studies. As several of the studies were largely qualitative or observational with small sample size, study conclusions will need to be validated with future prospective investigations. While the search strategy was not limited by studies in English language, there was a noted scarcity of non-English published articles using the identified search strategy in peer-reviewed journals. This may result in selection bias, as the field of transition medicine is much better understood in the global North, although the associated structural barriers are not.

CONCLUSION

Adolescence and young adulthood are critical periods in development and need to be viewed holistically in policy and programmes. There is little understood about how best to approach this care in resource-denied settings. This review illustrates prominent themes in order to do so and supports the need for international attention to this population. Prior to establishment of formal HCT programmes, upstream attention must focus on addressing context-specific needs and structural barriers for the successful creation of an adolescent-responsive policy for safe transition from paediatric to adult care.

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