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Transition of headache care from childhood to adulthood: Focusing needs, barriers, and models of care. A position paper of the IHS Child and Adolescent Committee

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Abstract

Headache disorders are among the most common neurological conditions in children and adolescents, often continuing into adulthood and causing substantial personal and societal burdens. Yet, the transition from childhood to adult headache care remains under-addressed, with critical clinical practice, policy, and research gaps. This narrative review synthesizes existing evidence and expert perspectives to highlight the urgent need for structured, developmentally appropriate transition models in headache care. It explores the evolving clinical features of headache in adolescence, increased vulnerability to different comorbidities, and changing health system expectations. We present a needs assessment reflecting the educational, emotional, and practical demands of patients and families. We identify provider- and system-level barriers, such as insufficient training, limited structured protocols, and inequitable access to specialized care, as significant obstacles to effective continuity. Drawing from established transition of care frameworks in other neurological conditions (e.g., epilepsy), we propose a dual-pathway model for headache care. We suggest key recommendations for clinicians and policymakers to promote anticipatory, patient-centered, and equitable developmental care strategies. International collaboration is essential to establish standardized guidelines and research priorities supporting optimal long-term outcomes and sustained quality of life for young people with headache disorders.

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Introduction

Headache disorders are highly prevalent in children and adolescents, with substantial variability in subtype and frequency across geographic regions. The estimated global prevalence in this age group is 58.4%, with higher rates among girls (1–3). In Europe, prevalence ranges from 24.2% to 88%, while in Asia it ranges from 3.5% to 63% (1,2). The Middle East shows variability between 19.4% and 68.8% (2,3). Although limited data exist for Sub-Saharan Africa, studies from Cameroon, Ethiopia, and Zambia indicate a significant burden of headache in youth, but specific migraine data remain sparse (2,4). In North America, prevalence ranges from 57.9% to 78%, with migraine affecting 8–23% depending on age and population (4,5). South American data show similarly high prevalence, with Brazil reporting 80.6% (2), and recent school-based surveys in Australia estimate prevalence rates around 60%, with migraine affecting 15–18% of adolescents (2,5).

Migraine is a disease that crosses all ages, and the presentation in children and adolescents reflects their developmental stage. These differences reflect the neurodevelopmental maturation of brain systems involved in pain modulation, emotional regulation, and sleep–wake control (6,7). For example, children or adolescent migraine attacks are typically shorter in duration (1–48 vs. 4–72 h), less commonly hemicranial, often associated with nausea (60% vs. 90%), and more likely to be relieved by sleep (6–8). Aura features are also more variable, and attacks tend to occur later in the day and more frequently during school days than weekends (6–8).

Such developmental distinctions underscore the need for age-appropriate, continuity-based approaches to care. Transition from childhood to adulthood headache services is more than a transfer—it is a maturation-informed process that must account for evolving biological, cognitive, and psychosocial needs (7–9). Management strategies that are effective in childhood may no longer be appropriate in adulthood, especially as some patients experience increasing headache frequency, severity, or comorbidity during this period. Additionally, family involvement often changes, and adult care systems may not be prepared to accommodate patients with complex developmental and psychosocial needs (9).

This narrative review, developed by members of the IHS Child and Adolescent Special Interest Group through a structured literature review and expert consensus, aims to:

- Summarize the current epidemiology and clinical profile of childhood or adolescent headache relevant to transition planning;
- Examine the specific challenges faced during the transition to adulthood;
- Explore the evolving needs of patients and their families across developmental stages; and
- Identify provider- and system-level barriers to successful transition and continuity of care.

Each section reflects the perspective of contributing experts and is supported by relevant evidence, including structured database searches (e.g., PubMed, Web of Science) and, where applicable, expert opinion grounded in clinical experience.

Long-term effects and risk of progression in untreated childhood or adolescent headache

Headache disorders in childhood and adolescence not only affect quality of life in the short term but also carry a significant risk of chronic progression and long-term comorbidities when left untreated or inadequately managed. Untreated migraine, among the most common neurological disorders in children and adolescents, persists into adulthood in approximately 60% of cases, with a higher prevalence in women (OR 1.5–2.0), leading to significant health, social, and economic consequences (4,5). Long-term implications of untreated childhood and adolescent headache extend beyond pain recurrence and include a markedly increased risk of: a) headache chronification, particularly chronic migraine, b) psychiatric comorbidities, such as anxiety and depression, c) cognitive problems, and d) reduced quality of life.

Data from longitudinal cohorts suggest that children with frequent episodic headaches have a 30–50% risk of developing chronic daily headache by adulthood, especially when early treatment is delayed or inadequate (5). Key predictive factors for chronification include high baseline headache frequency, female sex, family history of migraine, comorbid psychiatric symptoms, and delayed or suboptimal treatment in early stages (9–11).

In addition to chronification, psychiatric comorbidities such as anxiety and depression are more prevalent among those with a history of untreated childhood migraine. Longitudinal studies show that children and adolescents with headache disorders are at higher risk of developing conditions such as anxiety, depression, and sleep disorders in adulthood. Individuals with a history of childhood migraine have been estimated to have a 2 to 3-fold increased likelihood of major depressive disorder and generalized anxiety disorder later in life (4,9). These, together with various sleep disturbances, can worsen headache burden and complicate treatment (4,5,9). The co-occurrence of emotional dysregulation and chronic pain in adolescence appears to establish long-term vulnerability to mental health decline.

Headache disorders during childhood and adolescence can negatively impact neurocognitive development, including difficulties with attention, working memory, and processing speed (1). Recent studies have demonstrated that children with frequent migraine are more likely to exhibit lower academic achievement, increased school absenteeism, and reduced participation in cognitively demanding activities (12,13). These functional impairments may persist over time, particularly in individuals with comorbid emotional distress or poor headache control. Adolescents with chronic headaches are also at greater risk of experiencing disruptions in educational trajectories, which can limit access to higher education and, subsequently, career advancement opportunities in adulthood (4,5,13). The cumulative effect of repeated absences, difficulty concentrating, and sleep disturbances due to pain may reduce academic confidence and long-term vocational potential. Evidence suggests that early diagnosis, individualized treatment planning, and collaboration between healthcare providers and schools can mitigate these cognitive and educational burdens (12,14).

Adults who experienced untreated headaches in childhood often report lower overall life satisfaction, higher levels of disability, and increased use of health services (5,6,13). The financial impact extends to reduced productivity at work, higher rates of absenteeism, and increased medical costs associated with the ongoing management of chronic headache disorders (3,4). Recent studies show that individuals with chronic migraine originating in adolescence have up to twice the number of primary care visits and emergency room encounters compared to those without a headache history (11,14). This group also demonstrates significantly lower scores in health-related quality of life measures, particularly in physical functioning, emotional well-being, and social participation.

All these long-term effects of untreated headaches underscore the importance of early identification, multidisciplinary intervention, and the continuity of structured care into adulthood. Integrating headache management into broader developmental and vocational support services—especially during the transition to adult systems—may improve individual life outcomes and broader socioeconomic impact (11–14). The long-term consequences of untreated or poorly managed childhood and adolescent headache disorders underscore the urgency of timely, developmentally informed intervention. However, navigating the transition from childhood and adolescence to adult care introduces a distinct set of challenges that often disrupt continuity of care. The following section examines these transition-related challenges from developmental, structural, and provider-specific perspectives, which are crucial to understanding where and why many patients experience care gaps.

Transitioning challenges

Developmental changes and clinical complexity

Accurate documentation of the evolving characteristics of headache disorders during the transition from childhood to adolescence is essential. Symptom profiles, triggers, and attack frequency often change with neurodevelopmental maturation, making longitudinal assessment challenging (10). Moreover, the instruments used to evaluate headache severity must be age-appropriate and validated for child populations (11). Adolescents undergo significant developmental milestones—including sexual maturation, identity formation, and psychosocial individuation—that shape both disease expression and healthcare engagement. While girls tend to reach puberty earlier (mean age 11–12 years) than boys (mean age 14 years), this earlier biological development in females has been associated with a corresponding earlier onset and chronification of migraine, particularly in high-income countries (15). As autonomy increases during adolescence, patients assume greater responsibility for their health decisions, including the use of medication. This shift requires careful education and communication to ensure safe and informed transitions in pharmacologic care (15,16). Notably, female adolescents are disproportionately affected by migraine chronification and psychiatric comorbidities, highlighting the need for gender-sensitive transition strategies.

In contrast, male adolescents may be less likely to report headache symptoms or engage in care, potentially leading to underdiagnosis and delayed treatment (16).

Structural differences in childhood vs. adult healthcare systems

Healthcare systems often lack structural continuity between childhood and adult services. For example, in the UK, individuals under the age of 16 receive childhood care with parental support; by the age of 18, they are expected to independently manage their appointments, medications, and insurance (16,17). This abrupt change is overwhelming for many, especially without structured preparation or multidisciplinary support. Best practice models increasingly view transition as a developmental process rather than a one-time transfer. This approach considers the young person's cognitive maturity, emotional resilience, disease complexity, and social context (14–16). While these recommendations are widely applied in epilepsy and other child neurology domains, headache-specific transition models remain scarce (see Table 1).

Table 1. Family-centered transition checklist for childhood and adolescent headache care.

Domain	Key Questions to Consider
Headache Literacy	- Does the family understand the biological nature of headache disorders?
Treatment Knowledge	- Are caregivers aware of acute and preventive treatment options, including off-label use?
Lifestyle and Environmental Triggers	- Can the family identify and help manage modifiable lifestyle factors (e.g., sleep, hydration)?
Healthcare Navigation	- Does the family know how to access adult neurology services and request referrals?
Communication Skills	- Are caregivers and adolescents prepared for direct communication with adult providers?
Shared Decision-Making	- Are treatment plans developed with input from both the adolescent and the caregivers?
Mental Health Awareness	- Are families informed about the psychological comorbidities and support resources?
Transition Timing Readiness	- Is the family aware of developmental signs indicating readiness to begin formal transition?
Support Resources	- Are families linked with peer support, advocacy networks, or counselling if needed?
Reproductive and Gender Health (for female adolescents)	- Is there awareness of treatment implications for fertility, pregnancy, and sexual health?

Barriers to effective transition

Systemic barriers

Smooth transition from pediatric to adult care is crucial for ensuring the continued provision of high-quality healthcare and developmentally appropriate services as adolescents progress into adulthood (18–20). While consensus statements have underscored the importance of Transition of Care (ToC), a significant gap persists in developing structured protocols for children-to-adult care (20,21). This deficiency in structured ToC interventions is associated with adverse outcomes, including medical complications, poor adherence, discontinuity of care, patient dissatisfaction, increased emergency department and hospital utilization, and elevated healthcare costs. Systemic barriers impede adequate maturation to adult care, notably the absence of standardized protocols, long waiting lists in public healthcare systems, or the loss of insurance coverage (22). These combined factors represent the second most prevalent barrier domain, following emotional and relational barriers (23). Currently, no standardized protocols guide the developmental progression of headache care from children to adult settings (24). This lack of guidance results in inadequate communication and coordination between childhood and adult clinicians, a scarcity of dedicated transition services, limited access to adult primary and specialty care providers, and unfamiliarity with available community resources (22,24).

Although consensus guidelines for the developmental progression from children to adult neurological care offer a general framework, standardized headache care protocols require additional specific elements (10,11). These include:

- A comprehensive handover of headache diagnoses and current headache profiles,
- Prior neuroimaging and laboratory results,
- Past experiences with acute and preventive treatments,
- Patient education on adult-approved therapies not previously available due to age-based restrictions,
- For female patients, discussions related to contraception, pregnancy, and lactation.

In some countries, insurance challenges may pose a substantial obstacle to successful ToC, as individuals age out of eligibility for publicly funded or parent-sponsored insurance plans. Moreover, many adult neurologists may not accept publicly funded coverage, further complicating access to care. Loss of insurance coverage creates difficulties in obtaining affordable insurance, finding adult providers who receive public insurance, and managing increased out-of-pocket medical and medication expenses (23). These insurance-related challenges contribute to poor continuity of care, treatment delays, and increased reliance on emergency departments for routine healthcare needs (25). Developing transitional care pathways that include insurance counselling and navigation support may mitigate these risks.

Provider barriers

A significant obstacle to adequate transition in childhood and adolescent headache care lies in the lack of preparedness of adult healthcare providers for such services. This knowledge gap can result in suboptimal care or discontinuation of previously effective treatment strategies when patients move to adult services. A survey-based data, which was conducted among European headache centers, found that less than 30% of adult neurologists felt confident in managing adolescents with chronic headache disorders, citing limited exposure during training and uncertainty regarding developmental aspects of care (10,11).

Moreover, healthcare professionals often resist adopting novel, interdisciplinary, or youth-centered models of care. Despite emerging evidence supporting structured processes and personalized treatment plans, adherence to these frameworks remains inconsistent across institutions and countries (2,10). Institutional culture and workload pressures further compound this resistance. Improving provider readiness must be embedded into broader structural reforms to achieve effective transition models.

Patient barriers

Multiple patient factors may affect the transition process toward adult care providers. Patients and their families may also experience emotional reluctance, uncertainty, or resistance to leaving long-standing trusted relationships with childhood or adolescent providers (23,26,27). Adolescents transitioning into adulthood may also struggle with new responsibilities such as navigating health insurance, attending medical appointments independently, and self-administering medications—factors that can lead to treatment non-adherence if not adequately addressed. Health literacy and disease insight are critical in shaping patient engagement during transition (18,21).

Models of care

Current models

A universally accepted, standardized model for transitioning from childhood to adult specialized medical care for headache disorders has not yet been established (11). Because episodic migraine typically requires only basic therapeutic oversight, patients are often shifted to adult services without structured planning and with little consideration of their developmental stage or evolving care needs (28–30). Multidisciplinary and developmentally informed ToC models are essential for these individuals. Structured transition strategies have been implemented in other neurological conditions, such as epilepsy, and can be adapted for the care of childhood and adolescent headaches (18). Such models emphasize early preparation—ideally starting around age 13—with ongoing assessment and support.

Key tools include:

- Patient- and parent-completed self-care assessment forms,
- Defined transition goals,
- Medical summaries,
- Emergency care plans,
- Formal transfer letters and checklists.

This framework extends beyond neurologist referral. Adult providers may include psychiatrists, primary care physicians, and social support services. Coordination between child and adult neurology teams is often essential. Including a designated care coordinator or case manager improves outcomes by facilitating timely referrals, ensuring documentation transfer, and providing psychosocial support (1,31). Emerging evidence suggests that structured ToC models may differ significantly between academic and non-academic institutions, with academic centers more likely to implement standardized protocols, interdisciplinary collaboration, and evaluation metrics. In contrast, non-academic settings often face resource limitations that constrain comprehensive transition planning. Teams equipped with transition coordinators are more likely to achieve structured transition planning and successful linkage with appropriate adult services, including mental health, reproductive health, and financial assistance when necessary (see Table 2) (32).

As shown in Table 2, while direct headache-specific models are lacking, valuable insights can be drawn from ToC experiences concerning other diseases. Epilepsy-based transition frameworks are especially informative given the chronic, often unpredictable nature of the disorder and its shared psychosocial burden with migraine and other headache disorders. In contrast, models from diseases with steady progression, like cystic fibrosis or Duchenne muscular distrophy (DMD), may require adaptation due to the episodic and variable course of headache. Understanding these models' structure, benefits, and limitations is essential for guiding future efforts to design a tailored, multidisciplinary headache transition protocol (32,33).

Despite these promising frameworks, the limitations of current transition models—when considered for application in headache care—are noteworthy:

- Lack of disease-specific adaptation: Most models are developed for progressively worsening or organ-specific conditions. Headache disorders, being episodic, require models that accommodate fluctuating symptom severity and patient needs over time (32,34).
- Insufficient integration of psychosocial and behavioral components: Many models do not address mental health comorbidities, reproductive health counselling, or academic/career planning, all of which are crucial in adolescent headache care (34,35).
- Resource and training limitations: Effective implementation of structured models often requires trained transition coordinators, interdisciplinary clinics, and digital infrastructure, which are typically unavailable in many non-academic or resource-limited settings (36).
- Limited focus on patient autonomy and education: Models often overlook health literacy building and fail to shift care responsibility from parents to adolescents progressively (37).

Taken together, these limitations underscore the urgent need to develop headache-specific, developmentally appropriate transition frameworks.

Table 2. Summary of transition models in other neurological conditions and their applicability to headache care

Condition	Transition Model Overview	Key Components	Reported Benefits	Reported Limitations	Applicability to Headache
Epilepsy	Structured multidisciplinary ToC programs starting at age ~ 13	Transition coordinator, individualized care plans, co-led visits	Improved adherence, reduced emergency visits	Resource-intensive, inconsistent use across centers	High – similar chronicity and psychosocial impact
Cystic Fibrosis	Integrated respiratory-pulmonary transition clinics	Joint child–adult provider teams, digital health tracking	Seamless care, lower treatment drop-out	Focused on organ-specific care; less psychosocial focus	Moderate – some structural elements can apply
Duchenne Muscular Dystrophy	Consensus-based international Delphi model	Multi-stakeholder input, timeline-based goals	Structured and measurable transition process	Less emphasis on episodic symptom management	Moderate – developmental progression is useful
Type 1 Diabetes	Behavioral coaching and peer mentoring	Empowerment modules, digital reminders	Increased patient engagement	Requires high health literacy	Limited – headache lacks clear daily biomarkers
Juvenile Rheumatoid Arthritis	Rheumatology–primary care joint clinics	Continuity across medication regimens	Preserved pharmacologic consistency	Adult clinics often lack youth focus	Moderate – relevant for chronic medication users

Recommendations

Healthcare providers

Workshops, continuing medical education modules, and interdisciplinary training programs should be developed and promoted by professional societies. Beyond education, the developmental care plan should include structured, joint consultations between pediatric and adult teams. These meetings foster direct communication with patients and families, clarify treatment goals, and promote shared decision-making. In these consultations, the respective roles of the pediatrician, adult neurologist, nurse coordinator, and psychologist should be clearly defined (36).

Another critical consideration is striking a balance between increasing patient autonomy and maintaining continued parental involvement. While the transition process should promote independence in managing health, nephrology and cystic fibrosis care evidence shows that sustained parental support during adolescence contributes to better treatment adherence and psychosocial outcomes (38). Thus, families should be gradually empowered and informed to support this evolving role.

Policy makers

First and foremost, policymakers must recognize that adolescents with headache disorders represent a medically underserved population with complex healthcare needs. These often require coordinated, multidisciplinary, and developmentally informed care for successful long-term disease management (1). In this context, ineffective or nonexistent maturation policies harm patients by compromising health outcomes (39–43).

The consequences of inadequate policies are substantial, from increased emergency department visits to loss of therapeutic continuity, delayed diagnoses, and mental health deterioration (2). However, the optimal path to implementing developmental headache care policies remains underdefined (see Table 3).

From this point of view, we suggest that policymakers should:

1. Promote the development and adoption of transition guidelines specific to national headaches. They should be implemented across health systems;
2. Encourage interdisciplinary care models through healthcare financing plans and reimbursement policies;
3. Support headache-focused education programs and shared care protocols for pediatric and adult service providers;
4. Allocate resources for dedicated transition coordinators and digital tools to monitor and support the continuity of patient care;
5. Ensure equal access to expert care regardless of insurance coverage or geographical location.

Table 3. Considerations for policymakers in planning the development of care policies for youth with headache disorders, as outlined in the American Academy of Neurology's transition consensus statement (2).

Concept	Implementation recommendations
Effective transition of care requires additional clinician time.	Clinicians should be supported in scheduling longer and/or additional patient visits for youth with complex headache care needs starting at age ~13 when transition planning begins. Clinicians should be compensated for non-clinical hours spent on transition of care planning (e.g., transition planning meetings with other providers, time spent completing transfer packets).
Headache transition planning is a multidisciplinary process.	To support effective transition of care, youth with complex headache care needs will require input from not only the headache care provider, but also from other providers including social workers (for occupational and financial planning), education consultants (for planning effective transitions to higher education), primary care providers (for transition coordination), and mental health providers (for transition of mental health care). Policymakers should advocate for youth access to all the providers required to support the multidisciplinary transition of care effectively.
A medical home facilitates the transition process.	Policymakers should advocate for policies that ensure that every youth with a headache disorder has a primary care provider who can facilitate and coordinate their transition of care process
Timely access to adult headache care is a priority.	Policymakers can ensure more successful outcomes for youth with headache disorders by advocating for policies that facilitate access to trained adult headache providers promptly
Communication between the childhood and adult headache care teams is critical to effective transition.	Policymakers can work with providers to ensure access to the resources required to facilitate effective interprofessional communication in their specific care context (e.g., clinical space for transition meetings, transition clinics where the childhood and adult providers share a patient visit, additional administrative time to complete transfer packets)

Thinking forward, policymakers should also advocate for better research funding. It is well-documented that headache disorders are among the top three most underfunded diseases when comparing allocated research dollars to the disease burden (44–46). This underinvestment has direct consequences in that it impedes the development of evidence-based transition strategies. To address this deficiency, policymakers should prioritize increased research funding into childhood and adolescent headache disorders, explicitly focusing on transition-related outcomes and models of care. This investment would support longitudinal cohort studies, implementation science, and interventional trials necessary for establishing developmental care frameworks (19,38,39,41,44,46).

Final proposal of the IHS Child and Adolescent Committee

The STAR Questionnaire, a validated instrument for evaluating transition readiness, provides a structured basis from which headache-specific checklists may be developed to guide patients and caregivers through the transition process (33).

These interactions may include:

- Joint team meetings for shared patient review;
- Co-led visits to familiarize families with the adult care team;
- Joint documentation and case tracking protocols;
- Active engagement of the patient in shared decision-making to support autonomy and self-management skills;
- Discussion of female-specific considerations, such as menstrual migraine, contraceptive planning, and reproductive health, which often gain new clinical relevance during late adolescence.

Technological tools can enhance continuity and engagement, such as:

- Digital care plans embedded in electronic health records;
- Headache tracking applications with customizable symptom diaries;
- Automated alerts to monitor adherence or flare-ups (34,35).

To integrate clinical, psychosocial, and systemic dimensions of care transition, we propose a dual-pathway transition model (Figure 1). This model offers a structured foundation for designing and evaluating future transition protocols and supports advocacy for scalable, evidence-driven solutions in children and adolescents' headache medicine.

In this model, potential maturation barriers — including system fragmentation, provider-related limitations, and patient or family hesitations — are also highlighted as elements needing targeted solutions. This dual-pathway model

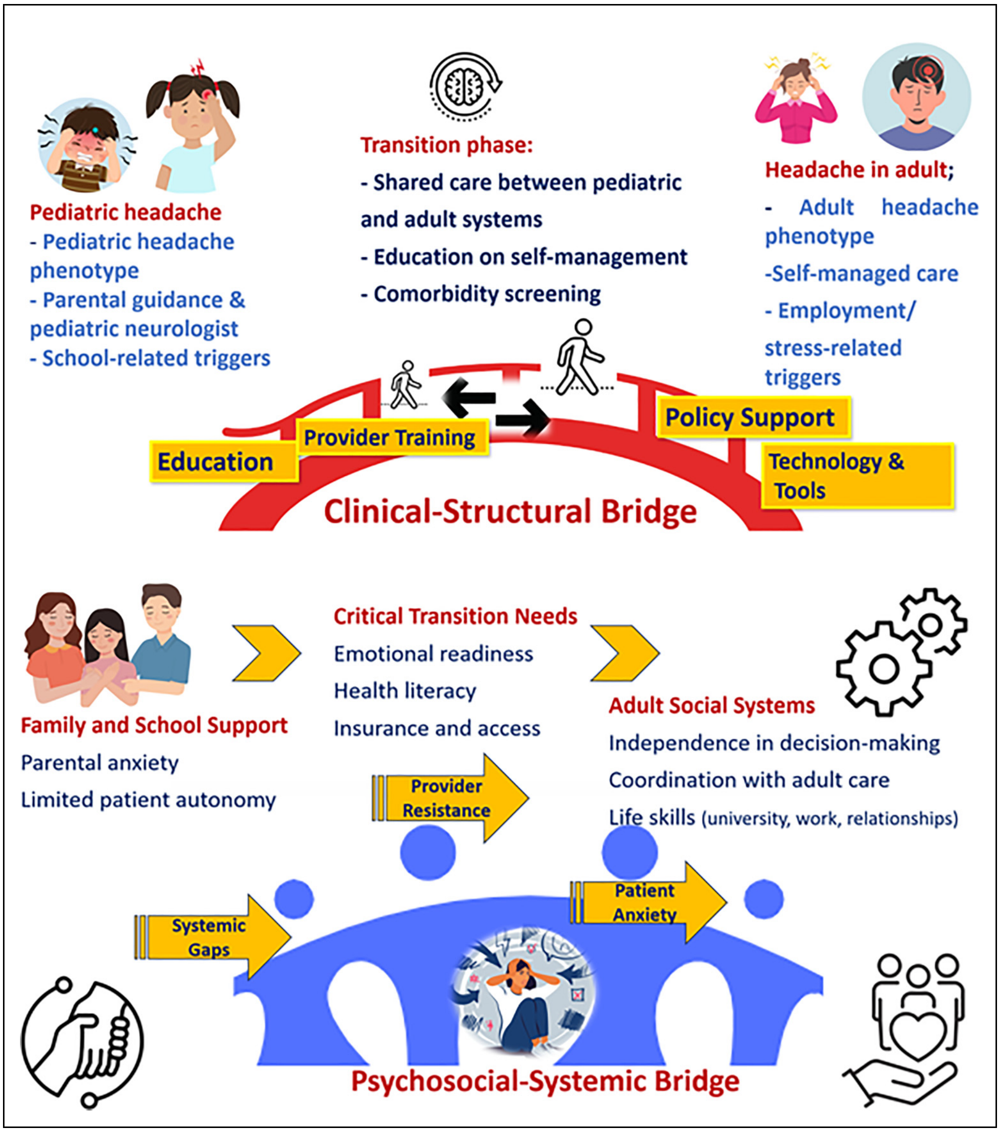

Figure 1. Bridging pediatric and adult headache care: a dual-pathway transition model.

is intended as both a conceptual framework and a practical tool to guide future clinical strategies and policymaking in developmental headache care. It underscores the necessity of coordinated, personalized, and age-appropriate interventions to ensure effective continuity and optimized long-term outcomes for adolescents and young adults living with chronic headache disorders.

Future innovations may also include integrating AI-driven predictive models, which are already emerging in the management of adult migraine, to guide treatment adjustments and identify patients at risk for treatment failure (36,46,47).

Conclusions

The transition from pediatric to adult headache care is a critical yet underrecognized developmental process that significantly impacts long-term outcomes for individuals with primary headache disorders. Although childhood and adolescent headache, particularly migraine, is not merely a transient childhood condition but often the early phase of a lifelong neurological disorder, structured transition models remain lacking, and many young people continue to face fragmented care, limited provider expertise, and a lack of continuity during a vulnerable period of psychosocial development. Barriers across systemic, provider, and patient domains—including insufficient adult provider training, inadequate coordination, and limited family support—hinder successful transitions. These gaps are especially concerning given the elevated risk of long-term disability, psychiatric comorbidities, and reduced quality of life associated with poorly managed adolescent headache disorders.

This paper calls for a paradigm shift from episodic, unstructured care transfers to longitudinal, developmentally informed, and multidisciplinary care pathways. Key components of this shift include enhanced provider education, family-centered transition planning, integration of digital tools, and health policy reforms to support equitable and sustainable care models.

Future directions must prioritize longitudinal research, health system innovation, and consensus-building efforts led by international headache societies. Investing in structured, personalized, and evidence-informed developmental care strategies can transform the lived experience of young people with headache disorders and promote lifelong brain health.

Public health relevance

- Headache disorders are a leading neurological condition in children and adolescents, but the transition to adult care is often neglected, leading to significant gaps in clinical practice and research.
- To address this gap, a new dual-pathway model is proposed, offering key recommendations for clinicians and policymakers to improve patient-centered care and ensure better long-term outcomes.

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