Original Article

Psychosocial Contradictions in the Transition to Adulthood for Patients with Congenital Heart Disease – A Qualitative Study

Abstract

Background: While survival into adulthood among individuals with congenital heart disease (CHD) has markedly improved, the psychosocial challenges accompanying the transition to adult care remain underexplored, particularly in diverse cultural contexts. This study explored the lived experiences and psychosocial contradictions of young adults with CHD in Iran, emphasizing the influence of cultural and systemic factors on this transition. **Materials and Methods:** A qualitative descriptive approach was used to capture the experiences of 15 individuals aged 16–40 years, who were diagnosed with CHD, along with five family caregivers and six healthcare providers (HCPs). Semi-structured interviews were conducted and analyzed through conventional content analysis to identify key patterns and underlying meanings within the narratives. Data management and systematic coding were facilitated via MAXQDA (version 2020). **Results:** Four main themes revealed profound psychosocial contradictions: (1) “Caught between Independence and Fear,” describing the struggle between autonomy and anxiety over leaving pediatric care; (2) “Hidden Illness, Visible Self,” highlighting the dissonance between outward appearance and internal limitations; (3) “Identity in Question,” involving uncertainty in self-perception shaped by chronic illness; and (4) “Navigating an uncertain future,” capturing concerns about long-term health, relationships, and life planning. **Conclusions:** This study revealed that transitioning to adulthood with CHD is fraught with psychosocial contradictions extending beyond clinical management. Our findings highlight an urgent need for holistic, culturally tailored support systems in Iran that integrate psychosocial well-being with clinical continuity. These insights can empower healthcare providers, families, and policymakers to develop more empathetic and effective transition strategies, including culturally sensitive counseling and improved access to information.

Keywords: *Adult, chronic illness, congenital heart disease, pediatrics, psychology, qualitative research, transitional care*

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Introduction

Congenital Heart Disease (CHD) is one of the most prevalent congenital anomalies, affecting approximately 1% of live births worldwide.[1] Advances in diagnostic and interventional cardiology have significantly improved survival rates, with over 90% of individuals with CHD now living into adulthood.[2] While this is a remarkable medical success, it presents new challenges. Specifically, the transition from pediatric to adult healthcare systems requires complex psychological, social, and emotional adjustments.[3]

Adolescence is a critical developmental stage characterized by rapid physical, psychological, and social changes as individuals strive for autonomy and identity.[4] For adolescents with CHD, this journey is complicated by frequent hospitalizations, multiple surgeries, long-term medication use, and physical limitations, all that shape self-perception and amplify the challenges of transitioning to adult care.[5,6]

Although research has increasingly addressed the psychosocial aspects of CHD, substantial gaps remain. Most studies emphasize clinical outcomes such as adherence and clinic attendance, while underexploring the deeper emotional and existential conflicts that accompany transition.[7-9] For example, adolescents and young adults often experience contradictions between a desire for independence and reliance on pediatric providers or between appearing outwardly healthy and managing

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an invisible chronic illness. These tensions affect not only identity formation but also adherence, well-being, and long-term adjustment.

The transition from pediatric to adult care is recognized internationally as a vulnerable period for individuals with chronic illnesses, including CHD. Studies indicate that up to 50% of adolescents with CHD fail to complete this transfer, leading to loss to follow-up and adverse outcomes.[10] Despite guidelines from organizations such as the American Heart Association and the American Academy of Pediatrics, many patients still report feeling unprepared for the self-management demands of adult care. Emotional barriers—such as fear of the unknown, grief over leaving trusted providers, familial overprotection, and social stigma—remain common obstacles.[11,12]

However, qualitative studies that focus on the voices of adolescents and young adults with CHD are still limited, especially those examining the psychosocial contradictions that accompany transition.[6,13-15] A deeper understanding of these lived experiences is critical for developing transition programs that address not only medical continuity, but also emotional resilience, identity formation, and social participation. Furthermore, most existing evidence comes from North America and Europe, with relatively little attention given to how cultural and healthcare system contexts shape these experiences. This highlights the need for studies in regions such as Iran, where family dynamics and systemic structures may significantly influence the transition process.[7,16]

Therefore, the present qualitative study aims to explore the psychosocial contradictions experienced by adolescents and young adults (aged 16–40) with CHD during their transition from pediatric to adult care. This broad age range was chosen deliberately to conceptualize the transition not as a single event but as a protracted life-course process. It allows for the inclusion of perspectives from those anticipating the shift, those actively navigating its challenges, and those reflecting on its long-term impacts. By situating these multifaceted experiences within the Iranian healthcare context, this study contributes both locally and internationally by broadening the understanding of how cultural, emotional, and social dimensions intersect with clinical transition processes.

Materials and Methods

This qualitative study, conducted in 2024, employed conventional content analysis (CCA) to explore the lived experiences of individuals with CHD during their transition to adulthood. CCA, as described by Graneheim and Lundman,[17] was selected because of its suitability for examining underexplored phenomena and its flexibility in allowing categories and themes to emerge directly from the data. This approach enabled a rich, participant-centered understanding of psychosocial contradictions. To ensure methodological rigor, the study adhered to the COREQ (COnsolidated criteria for REporting Qualitative research) checklist.[18]

This study was grounded in a naturalistic, interpretivist paradigm, which posits that reality is socially constructed and can be understood only through the subjective experiences of individuals within their context. This philosophical stance directly informed the selection of the CCA. Because interpretivism seeks to understand the world through the eyes of the participants, a method was needed that would allow themes to emerge inductively from their narratives rather than being imposed by a preexisting theory. CCA is ideally suited for this purpose, as its emphasis on interpreting both manifest (explicit) and latent (underlying) content facilitates a deep exploration of the meanings that individuals with CHD attribute to their psychosocial challenges.

This study was conducted in diverse cardiac care settings across Iran, and the participants were primarily recruited from pediatric and adult cardiology clinics in urban and semiurban areas. All interviews were held in quiet, private locations to ensure confidentiality and promote open dialog.

Participants and Recruitment: Participants were recruited via purposive sampling to ensure maximum diversity in terms of age, disease severity, and healthcare experience. The sample included patients with CHD (aged 16–40), family caregivers (FCs), and healthcare professionals (HCPs). The inclusion of participants aged 16–40 years was a deliberate methodological choice, reflecting a life-course approach designed to capture the transition not as a single event but as a protracted psychosocial process. This broad age range allowed for the inclusion of participants from three distinct experiential phases: those anticipating the shift in late adolescence, those actively navigating it in their twenties, and those able to reflect on its long-term impacts in their thirties. This approach was chosen to provide a holistic understanding of the phenomenon rather than to compare subgroups.

The inclusion criterion was the ability to provide informed consent, whereas the exclusion criterion included cognitive impairments that would hinder meaningful participation.

Recruitment occurred through cardiology clinics, patient support groups, and social media platforms. The research team acknowledges that recruitment via social media may introduce potential sampling bias, possibly attracting participants, who are more digitally literate or actively engaged in patient communities. To mitigate this, we supplemented this approach with clinic-based recruitment to capture a broader range of experiences.

Participant characteristics

Table 1 presents the demographic and clinical characteristics of the participants.

Data were collected between September 2024 and June 2025 through in-depth semi structured interviews conducted in person based on participants' preferences for time and location. Twenty-six individuals participated (15 AYAs with CHD, 5 FCs, and 6 HCPs), with three interviewed twice for clarification, for a total of 29 interviews. The interview guide was developed from the literature and expert input. The initial questions included "Can you describe your experience transitioning from pediatric to adult care?," "What challenges have you faced managing your condition independently?," and "How has this transition affected your emotional and social life?" The guide was expanded to include emerging themes such as "Have you felt caught between wanting independence and needing protection?" Probing questions such as "Can you give an example?" and "How did that make you feel?" were used to deepen the responses. Each interview lasted between 30 and 60 min and was conducted in Persian by the first author, a PhD candidate in nursing with clinical experience in pediatric cardiology. The interviews were audio-recorded with participants' consent and supplemented by field notes capturing nonverbal cues. Three participants consented to be interviewed but not to audio recording. In these instances, comprehensive real-time notes were taken, and key points were verbally summarized with the participant for confirmation at the end of the session. While this approach may result in a potential loss of verbatim richness compared with transcribed audio, it was essential for ensuring participant comfort and inclusion. Data collection continued until thematic saturation was achieved, confirmed when three consecutive interviews produced no novel codes, categories, or variations in theme content, suggesting informational redundancy.

This study utilized a conventional qualitative content analysis approach as described by Graneheim and Lundman to interpret participants' experiences systematically and inductively. This method is well suited for exploring phenomena where limited prior theoretical knowledge exists—such as the psychosocial contradictions encountered by individuals with CHD during their transition to adulthood.

The audio-recorded interviews were transcribed verbatim, and all the transcripts and notes were read repeatedly for immersion. The analysis began by identifying and condensing meaning units from the text, which were then

Table 1: Demographic characteristics of the study participants

ID	Age	Gender	Marital status	Diagnosis in the medical record	Region	Role
P1	40	Female	Married	ASD*	City	Patient
P2	20	Female	Single	VSDs**	City	Patient
P3	19	Male	Single	Mitral Atresia	Town	Patient
P4	19	Male	Single	ASD	City	Patient
P5	19	Male	Single	TOF***	Town	Patient
P6	29	Male	Single	Ebstein's Anomaly	Village	Patient
P7	20	Female	Single	TOF, PI	Town	Patient
P8	40	Male	Married	TOF	Town	Patient
P9	32	Male	Single	ASD	City	Patient
P10	40	Female	Married	Ebstein's Anomaly	Town	Patient
P11	16	Male	Single	CCTGA****	City	Patient
P12	39	Male	Married	ASD, PH*****	Town	Patient
P13	19	Female	Single	VSD	Village	Patient
P14	16	Male	Single	CoA[$]	City	Patient
P15	35	Female	Married	ASD	Town	Patient
H1	41	Female	Married	–	City	The PICU head nurse
H2	63	Male	Married	–	City	Cardiologist
H3	45	Female	Married	–	City	Cardiologist
H4	51	Female	Married	–	City	Cardiologist
H5	46	Male	Married	–	City	Social worker
H6	42	Female	Married	–	City	Nurse
F1	36	Female	Married	–	City	Mother of patient with COA
F2	46	Female	Married	–	City	Mother of patient with MA[$$]
F3	52	Male	Married	–	City	Father of patient with TA[$$$]
F4	37	Female	Married	–	Town	Spouse of patient with TOF
F5	19	Male	Single	–	Town	Daughter of patient with Ebstein's Anomaly

*ASD: Atrial septal defect, **VSD: Ventricular septal defect, ***TOF: Tetralogy of fallot, ****CCTGA: Congenitally corrected transposition of the great arteries, *****PH: Pulmonary hypertension, [$]CoA: Coarctation of the Aorta, [$$]MA: Mitral atresia, [$$$]TA:Tricuspid atresia

assigned initial codes. These codes were grouped into conceptually similar subcategories and categories. During the abstraction and theme development phases, the research team placed particular emphasis on ensuring analytical clarity and conceptual boundaries between overlapping categories. For example, while “Fear of the Future” (Theme 1) captured participants’ immediate emotional reactions—such as anxiety, hopelessness, and fear of death when facing uncertain clinical outcomes such as surgery or mortality—“Navigating an Uncertain Future” (Theme 4) reflected participants’ adaptive or maladaptive coping processes in response to ongoing uncertainty, including avoidance, denial, and attempts to plan for unpredictable life trajectories. This deliberate distinction helped prevent thematic overlap and ensured that each theme represented a unique level of meaning: Theme 1 emphasized emotional experience, whereas Theme 4 emphasized behavioral and cognitive adaptation. This systematic process resulted in the extraction of 572 initial codes, which were consolidated into nine subcategories and, finally, four overarching themes. MAXQDA version 2020 was used to facilitate systematic data organization and retrieval throughout this process.

Trustworthiness was established using Guba and Lincoln’s[19] criteria. Credibility was achieved through prolonged engagement, data source triangulation, member checking, and peer debriefing. Dependability was enhanced by a detailed audit trail. Transferability was supported by rich contextual descriptions. Confirmability was strengthened via external audits and reflexive practices.

The research team engaged in critical reflexivity, paying special attention to the researchers’ backgrounds in pediatric care. Importantly, none of the team members had a current or prior clinical relationship with any of the study participants. This separation of roles was crucial for minimizing the potential for bias and fostering an open environment where participants could share their experiences candidly without fear of influencing their clinical care. Despite this separation, researchers with pediatric backgrounds were mindful that their clinical knowledge could shape their interpretations. This background provided certain advantages, such as a deeper contextual understanding of the clinical and emotional realities faced by young people with CHD, allowing for more nuanced interpretations of participants’ narratives. However, it also poses a potential risk of interpretive bias due to preexisting professional assumptions. To mitigate this, the lead researcher explicitly stated her role as a researcher (not a clinician) at the start of each interview and actively engaged in reflexive bracketing. This involved maintaining a reflexive journal to critically examine potential assumptions and document interpretive decisions, ensuring that the final themes were firmly grounded in the participants’ authentic voices rather than the researcher’s clinical lens. To manage this, the lead researcher explicitly stated her role as a researcher (not a clinician) at the start of each interview and used a reflexive journal to critically examine potential assumptions, ensuring that the final themes were firmly grounded in the participants’ unique perspectives.

Ethical considerations

The study received ethical approval from the Research Ethics Committee of Kashan University of Medical Sciences (ID: IR.KAUMS.MEDNT.REC.1403.047) and adhered to the Declaration of Helsinki. All participants provided written informed consent after being fully informed about the study. Participation was voluntary, and anonymity was protected by removing all personal identifiers from transcripts and generalizing demographic data in the final report.

Results

Content analysis of the interviews revealed four overarching themes that capture the psychosocial contradictions experienced by young people with CHD during their transition to adulthood: (1) Caught between Independence and Fear; (2) Hidden Illness, Visible Self; (3) Identity in Question; and (4) Navigating an Uncertain Future. The key findings for each theme are detailed below, and a simplified overview of the thematic structure is presented in Table 2.

Caught between independence and fear

This theme describes the central conflict between participants’ natural desire for autonomy and the profound anxieties tied to their health, future, and the demanding task of self-management. These tensions manifested through several interconnected struggles.

Pervasive fear of the future

The participants expressed deep-seated anxieties about their long-term health and mortality. These fears were tangible and shaped life decisions, as one young adult expressed: *“…I was so scared, I thought if I had the surgery, it would be the end for me. I constantly worried about what would happen if the operation was not successful or if something went wrong. I also feared death…”* (P6).

Fears related to marriage, childbearing, and occupation

The quest for independence was frequently undermined by fears of rejection in both personal and professional realms. Worries about social stigma affecting marriage prospects or physical limitations impacting employment are common. One participant recounted: *“…A while ago, I had a suitor. When he determined about my heart problem, he started pointing out a few other flaws and then left…”* (P7).

Paradox of support and independence

A key contradiction emerged from the tension between familial overprotection and the need to develop self-management skills. Although parents act out of love,

Table 2: Summary of the coded themes, subcategories, initial codes, and illustrative quotes.

Major theme	Subcategory	Initial codes (Examples)	Illustrative quotes
1. Caught Between Independence and Fear	Pervasive Fear of the Future	Fear of surgery, fear of disability/death, concern about lifespan Fear of worsening symptoms, feeling lack of control Feeling of permanent limitations	*"…Sometimes his lips turn blue and he cannot breathes; he turns black. I truly do not know how long he will live, and I am very scared…" (F4)*.
	Fears Related to Marriage, Childbearing, and Occupation	Fear of pregnancy implications (mother/child) Worry about miscarriage, fetal disability Fear of transmitting illness to child Worry about stigma in marriage, rejection Intense concern about losing partner Worry about finding/keeping stable employment Ambiguity in career prospects, ability to work Physical limitations/pain at work	*"…Sometimes, with the slightest shortness of breath I had notice in other children during play, my heart would sink, and I had get scared, thinking, 'What if they inherited it from me too?'"*(P8)
	The Paradox of Support and Independence	Parental overprotection, Resistance to medical advice, nonadherence as a form of independence, Reliance on family, desire for autonomy	*"…I know my illness is not curable. That is why I have no hope at all. Going to the doctor seems pointless to me. It does not make much difference whether I go or not…"* (P7)
2. Hidden Illness, Visible Self	Struggles with Disclosure and Misunderstanding by Others	Fear of disclosure, avoiding pity/judgment, Dissonance between appearance and reality, Concealing illness,	*"…People often offer unnecessary sympathy and useless advice. it is very bothersome…"* (P4)
	Concealment as a Coping Strategy	Active concealment of illness/scars, performing a "normal" identity, Avoiding unwanted attention, conflict between healthy appearance and actual illness	*".No one can tell I'm sick from the outside, so I prefer not to say anything."* (P6) "…erase the scar from this wound so the scar is not visible…" (P3).
3. Identity in Question	Impact of Childhood Medical History and Feeling Different	Feelings of fragility, internalized sense of limitation/abnormality, feeling alienated from peers, Missing out on youth, Formative memories of surgery/hospitalization, Continuous medical intervention, Illness as central to life narrative	*"…There are some cases where infants are operated on right after birth… This must be repeated, and that is their treatment process…" (H2)*
	Awareness and Understanding of Illness	Desire for more information, Seeking information (digital/other), Desire for control through knowledge, insufficient understanding of illness/treatments	*"… this artificial intelligence ChatGPT is very good now. I search for any topic or question I have about my illness…"* (P4)
4. Navigating an Uncertain Future	Coping Mechanisms for Uncertainty	Avoidance strategies, minimizing stress, attempt to deny illness, Minimizing seriousness, Emotional suppression, self-treatment of sign and symptoms	*"…I simply do not listen when someone says I have a heart problem. I just tell myself I am working, as if it is nothing…"* (P5)
	Adherence to Treatment and Perceived Futility	Inconsistent medical follow-up, questioning treatment efficacy, Hopelessness impacting adherence	*"…They were not doing anything for me. We go to the doctor once a year. In addition, every time we go, there are so many echoes and diagnostic tests that are useless to me…" (P6)*

this often fosters dependency, leaving young adults feeling unprepared for the future. *"…My dad and mom handle everything for me. I just study… I am truly terrified. What will happen after them?"* (P2).

Healthcare providers frequently observe this dependency and note its developmental implications:

"…Some of them are completely dependent on their families, making you feel like you're seeing a 5- or 6-year-old child rather than an 18-year-old child…" (H2).

Hidden illness, visible self

This theme addresses the psychological dissonance of appearing healthy while internally managing a life-altering chronic condition. This led to a significant burden related to disclosure and the constant need to perform normalcy.

Struggles with disclosure and misunderstanding

The participants carefully managed whether to reveal their condition, often choosing concealment to avoid pity, judgment, or discrimination. This negotiation was a consistent source of stress: "…She states that she tells no one she has a heart problem. Whenever she does, it just harms her more, and they reproach her…" (P7).

Concealing as a coping strategy

Actively hiding the illness was a primary method for maintaining a sense of normalcy and avoiding unwanted attention, highlighting the gap between internal reality and external presentation: "…I never tell people about my heart problem. On the outside, I look fine, but inside, I am always worried. If they knew, they would treat me differently, so I just pretend everything is normal…" (P3).

Family support often reinforces this strategy, with the following cultural implications: *"...He absolutely did not want anyone to know about his illness – not his friends, not his relatives… We supported that, knowing how people can react."* (F1).

Identity in question

This theme examines how a lifelong illness shapes one's sense of self. The "patient" identity often overshadows other personal attributes, complicating the formation of a cohesive adult identity.

Impact of childhood medical history and different feelings

The participants' identities were strongly influenced by early and often traumatic medical experiences. This fostered a persistent sense of being fundamentally different from peers and limited engagement in typical youth experiences: *"...I should also mention that I could not enjoy my youth like others; it was always about heart pain, shortness of breath, palpitations, and all that…"* (P6).

Awareness and understanding of illness

The participants' ability to develop a confident identity was also affected by inconsistent knowledge about their condition. Gaps in accessible information often undermine their sense of control and self-efficacy:

"Honestly, in society, I have not seen much about heart surgery… there's nothing, no information available…" (P4). This internalized sense of difference was reflected in healthcare providers' perceptions:

"…These individuals are constantly in hospitals and clinics; I do not know if they even truly live to reach adulthood…" (H3).

Navigating an uncertain future

This final theme encapsulates the pervasive uncertainty that color every aspect of the participants' lives. Lacking a clear roadmap, many struggled with how to plan for a future that was unpredictable.

Coping mechanisms for uncertainty

Faced with constant uncertainty, many participants resorted to avoidance or denial. The emotional toll was significant and often led to feelings of hopelessness. *"I do not research at all about my illness or how I got this way. Because the more I delve into these topics, the more distressed I become…"* (P3).

Adherence to treatment and perceived futility

This sense of an uncertain future also influences treatment adherence. For some, the perception that their condition was incurable led to a feeling of futility, impacting their engagement with long-term care, an observation confirmed by a healthcare provider: *"... When I do not know what will happen tomorrow, whether I will be alive or not, why should I think about how to come for continued treatment? What is the use of medicine or long-term treatment?"* (P7).

Discussion

This study illuminates the complex psychosocial contradictions faced by young adults with CHD during their transition to adulthood in Iran. Four interconnected themes emerged—"Caught between Independence and Fear," "Hidden Illness, Visible Self," "Identity in Question," and "Navigating an Uncertain Future." Together, these findings show how the universal challenges of chronic illness are uniquely intensified by Iran's cultural norms and systemic healthcare limitations.

Caught between independence and fear, the developmental drive for autonomy is persistently undermined by profound anxieties. Fear of the future, encompassing concerns about health deterioration and mortality, is well documented in the literature on CHD.[20] In the Iranian context, however, these fears are not abstract; they are reinforced by systemic barriers such as limited access to specialized adult cardiology care and high treatment costs, which cultivate a deep sense of hopelessness. This existential unease is further magnified by fears related to marriage, childbearing, and occupation. Within Iranian society, these milestones are considered essential markers of successful adulthood, and the stigma of a chronic condition intensifies concerns about rejection, thereby motivating concealment behaviors.[12,21] The dynamic of support versus independence further complicates this struggle, as familial overprotection—although well intended—often fosters dependency and stifles the development of self-management skills.[11,22] Additionally, a study in Kerman, Iran, revealed that anxiety and depression are common among adults with CHD and are associated with individual factors such as sex, age, and type of surgery.[23]

Hidden Illness, Visible Self, the experience of living with a concealed illness creates additional psychological strain. Appearing healthy while internally managing a chronic

condition produces ongoing dissonance, and struggles with disclosure and misunderstanding are central to this tension. As shown in prior research, stigma acts as a significant barrier to disclosure.[24] In Iran, where maintaining social harmony and family honor are highly valued, the decision to disclose one's illness is particularly fraught, as it is perceived as a burden. Concealment, therefore, is not merely passive avoidance but also an active strategy of survival, a performance of normalcy that protects social acceptance yet undermines authenticity. Similar studies in Saudi Arabia have shown that CHD has broad psychological effects on patients and their families, including anxiety and parental stress.[25]

In question, a lifelong illness also profoundly influences one's identity. Early and repeated medical encounters foster a "patient identity," reinforcing a sense of difference and limiting participation in the normative experiences of youth, findings that are consistent with the international literature.[26] Our study further highlights the role of illness awareness and understanding. The participants increasingly turned to digital tools, including AI, to seek information, reflecting a proactive search for agency. However, the scarcity of Persian-language and culturally tailored resources undermined this independence, leaving individuals dependent on family and clinicians for guidance. This lack of accessible information not only erodes health literacy but also complicates the formation of a confident adult identity. Grounded theory research in Saudi Arabia has indicated that children with CHD employ various coping strategies to align their identity with the limitations imposed by the illness.[27]

Ultimately, these contradictions converge on the challenge of navigating an uncertain future. Avoidance and denial were the most common coping mechanisms observed, whereas proactive strategies such as counseling were notably absent. This absence reflects both the cultural stigma attached to mental health services and the lack of integrated psychosocial support within Iran's cardiac care system.[28] The sense of uncertainty also shaped treatment adherence. Rather than interpreting nonadherence as personal failure, our findings frame it as a symptom of hopelessness, where ongoing care is perceived as futile in the face of incurability and systemic barriers. Another study in Iran highlighted that marital status, employment, and disease severity are associated with quality of life among adults with CHD, emphasizing the importance of social support and vocational planning.[29]

In sum, the transition to adulthood for young Iranians with CHD is not only a clinical process but also a profound psychosocial negotiation shaped by stigma, uncertainty, and systemic barriers. Addressing these challenges requires more than medical management; it calls for structured transition clinics, culturally tailored educational resources, and integrated psychosocial care. Bibliometric analyses indicate that regional research on CHD is limited, and this study can help fill this gap while providing a culturally and socially informed perspective.[30] Such reforms are critical to strengthening self-efficacy, improving adherence, and enabling young people to navigate adulthood with dignity, resilience, and hope.

Despite the rich insights gained from this qualitative study, several limitations warrant consideration. First, as a qualitative study, the findings are context-specific and not statistically generalizable to the broader population of young adults with CHD.

Second, the study was conducted in Iran, and the findings might be influenced by sociocultural norms and the specific structure of the Iranian healthcare system. While certain themes may resonate in other low-resource settings, these factors limit the direct transferability of some nuances of the experience to other cultural contexts.

Additionally, the study employed a maximum variation sampling strategy by including a wide age range (16–40). While this was a methodological strength that provided a rich, life-course perspective, a corresponding limitation is that the qualitative design does not permit formal comparative analysis between different age cohorts. The findings, therefore, describe the broad spectrum of experiences rather than quantifying differences between groups.

Finally, although the lead researcher had a clinical background in pediatric nursing, none of the research team members had a dual role (such as clinician or researcher), and there was no prior or current therapeutic relationship with the study participants. This separation of roles was maintained to minimize potential bias and foster an open environment for discussion.

Conclusion

This qualitative study illuminates the intricate psychosocial challenges young adults with CHD face during their transition from pediatric to adult healthcare. Four overarching themes—"Caught between Independence and Fear," "Hidden Illness, Visible Self," "Identity in Question," and "Navigating an Uncertain Future"—collectively reveal a complex tapestry of emotional, social, and existential contradictions beyond clinical management.

Our findings show that the pursuit of independence, a hallmark of young adulthood, is profoundly challenged by deep-seated anxieties related to health prognosis, family life, education, and employment. The tension between medical adherence and the desire for normalcy underscores the difficult self-management decisions these individuals must make. Moreover, well-intentioned familial overprotection often inadvertently hinders autonomy, underscoring the need for family-centered transitional support. The concealed nature of CHD further

complicates disclosure, fostering misunderstanding, stigma, and concealment at personal cost. These experiences shape identity formation, reinforcing feelings of difference and dependency, whereas a pervasive sense of uncertainty undermines future planning and adherence to medical care.

In conclusion, the transition to adulthood for individuals with CHD is a profoundly transformative period marked by psychosocial vulnerabilities that demand systemic attention. These findings highlight the need for holistic and practice-oriented interventions. Specifically, multidisciplinary transition programs should incorporate psychosocial professionals (e.g., psychologists, social workers, counselors) into cardiology clinics, provide structured family education to balance protection with autonomy, and create accessible Persian-language educational resources to strengthen health literacy. Policies that integrate vocational counseling, marriage and fertility guidance, and mental health services within CHD care pathways are equally critical. By embedding these strategies into transition planning, healthcare systems can move beyond clinical transfer to empower young adults with CHD to navigate adulthood with resilience, autonomy, and hope.

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Conflict of interest

Nothing to declare.

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