Understanding and Supporting the Transition to Adult Care Among Youth Living with Perinatally Acquired HIV in India: A Community-Based Participatory Research Approach

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Abstract

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India has one of the world's largest populations of youth living with HIV (YLHIV), yet their experience of transitioning from pediatric to adult care is poorly understood, particularly for youth raised in residential childcare institutions. Existing transition frameworks, largely derived from high-income settings, emphasize individual clinical self-management and may overlook the relational and cultural dimensions shaping transition in low- and middle-income countries. This thesis aims to explore how YLHIV in India conceptualize growing up, independence, support, and readiness for transition across clinical, psychosocial, educational, employment, and housing domains. A community-based participatory photovoice study was conducted at two Karnataka sites — Bengaluru (family-based and institutional care) and Belgaum (institutional care). Sixteen YLHIV aged 13–22 years (6 female, 10 male) completed orientation, photography assignments, and peer-facilitated focus group discussions. Transcripts were double-coded using a hybrid deductive-inductive approach (29 codes; Pooled Cohen's Kappa = 0.66, with all remaining disagreements resolved by consensus).Participants framed independence not as individual autonomy but as relational capacity to support family, reflecting collectivist values. Psychological "peace" emerged as central to successful adulthood. Although age 18 marked formal responsibility onset, participants advocated for earlier, developmentally-staged preparation. Stigma and non-disclosure limited

help-seeking even within supportive networks centered on family and institutional caregivers. Institutional-care youth described anticipatory grief about losing caregiving structures and community at discharge. Photovoice surfaced embodied experiences invisible to standard methods. Transition programming for YLHIV in India must be multidimensional, relational, culturally grounded, and developmentally staged from early adolescence, with targeted support for youth leaving institutional care. Findings will inform context-relevant transition readiness tools for LMIC settings.

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List of Abbreviations

AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Therapy
CBPR	Community-Based Participatory Research
CCI / CCIs	Childcare Institution / Childcare Institutions
FGD / FGDs	Focus Group Discussion / Focus Group Discussions
HCD	Human-Centered Design
HIV	Human Immunodeficiency Virus
ICR	Inter-Coder Reliability
IRB	Institutional Review Board
LMIC / LMICs	Low- and Middle-Income Country / Countries
NACO	National AIDS Control Organisation
NGO / NGOs	Non-Governmental Organization / Organizations
SHOWeD	See, Happening, Our lives, Why, Do (photovoice reflection framework)
UNAIDS	Joint United Nations Programme on HIV/AIDS
UW	University of Washington
YLHIV	Youth Living with HIV
YPLHIV	Young People Living with HIV
YRGCARE	YR Gaitonde Centre for AIDS Research and Education

Contents

1. INTRODUCTION

The global scale-up of antiretroviral therapy (ART) has transformed HIV from a fatal diagnosis into a manageable chronic condition, enabling children with perinatally and behaviorally acquired HIV to survive into adolescence and adulthood. This epidemiological success has created a programmatic challenge that health systems in many low- and middle-income countries (LMICs) are only beginning to address: the transition of youth living with HIV (YLHIV) from pediatric to adult healthcare services. Adolescence is itself a critical developmental period during which social determinants such a family environment, education, employment, housing, and peer networks exert profound influences on lifelong wellbeing;[1] for YLHIV, this developmental complexity is compounded by the demands of lifelong ART adherence, stigma management, the potential loss of trusted pediatric providers, and the absence of structured transition protocols in most settings.[2] Healthcare transition for YLHIV is therefore best understood not as a discrete clinical event but as a multidimensional process unfolding across multiple life domains simultaneously.[2] Prospective evidence confirms that unstructured transition is harmful: Tanner and colleagues documented significant disruptions in care engagement: gaps in retention, ART access, and viral suppression, in the year following transfer to adult care,[5] underscoring the urgency of structured, anticipatory transition support.

India presents a critical context for studying this transition. With one of the largest populations of YLHIV globally, India hosts the third-largest HIV epidemic in the world.[6,10,13] India's National AIDS Control Program has achieved substantial gains in ART coverage and progress toward UNAIDS 95-95-95 targets, but transition-specific programming for YLHIV remains underdeveloped, and the experiences of YLHIV navigating the move from pediatric to adult care are not well documented in the Indian literature.[6,13] Most existing transition literature originates from high-income settings where healthcare infrastructure, social safety nets, and cultural contexts differ markedly from India's reality.

A distinctive feature of the Indian HIV epidemic is the role of residential childcare institutions (CCIs), which provide housing, healthcare coordination, and psychosocial support to children orphaned or made vulnerable by HIV.[11] Many YLHIV in India have grown up in these institutional settings, where the

institution becomes their primary site of attachment, identity formation, and community. When YLHIV in institutional care reach the age of discharge, typically 18 years, they face a dual transition: clinical (pediatric to adult HIV care) and residential (institutional to independent living).[2,11] This dual transition has received almost no research attention internationally, yet it represents one of the most consequential periods in these young people's lives.

This study addresses these gaps through a community-based participatory research (CBPR) approach, using photovoice as a participatory visual method to explore how YLHIV in Karnataka, India, perceive and experience their readiness to transition from pediatric to adult care and from dependent to independent living across multiple life domains. The study builds on prior CBPR partnership work conducted with these communities,[8] and is part of a larger multidisciplinary, multi-institutional initiative involving Johns Hopkins University, YRGCARE, RISHI Foundation, and Sneha Charitable Trust to develop a comprehensive transition readiness tool that extends beyond clinical domains to encompass education, psychosocial, employment, and housing readiness. Existing transition tools have focused predominantly on clinical readiness and HIV self-management; for example, the Adolescent Transition Package evaluated in a cluster-randomized trial across four counties in Kenya was administered by routine clinic staff and consisted of standardized assessments and chapter books to guide provider–youth discussions at scheduled clinic visits, yielding measurable improvements in HIV literacy and self-management.[17] While valuable, such clinic-administered, biomedically-anchored tools do not systematically capture the educational, vocational, psychosocial, and housing dimensions that YLHIV and prior literature identify as central to a successful transition into adulthood. The present study seeks to surface those broader dimensions from the perspective of youth themselves, providing an empirical foundation for a more multidimensional readiness tool. The use of CBPR principles ensures that YLHIV are positioned as co-producers of knowledge rather than passive participants, reflecting ethical commitments to youth partnership and methodological rigor.[8,9]

2. BACKGROUND

India is home to the third-largest HIV epidemic globally, with an estimated 2.4 million people living with HIV.[6,10,13] Substantial investment through the National AIDS Control Program has achieved significant ART scale-up and progress toward UNAIDS 95-95-95 targets,[6,12] but as perinatally-infected children survive into adolescence and adulthood in growing numbers, the transition from pediatric to adult HIV care has emerged as a critical programmatic gap. Transition-specific programming for YLHIV remains underdeveloped in India, and the lived experiences of YLHIV navigating this move are not well documented in the Indian literature.[13]

A distinctive feature of the Indian epidemic is the role of residential childcare institutions (CCIs), facilities operated by NGOs, faith-based organizations, and state governments , which provide housing, healthcare coordination, and psychosocial support to children orphaned or made vulnerable by HIV.[11] Many YLHIV in India have grown up in these institutional settings, which become their primary sites of attachment, identity formation, and community. Upon reaching the age of discharge, typically 18 years, these young people face a dual transition: clinical (from pediatric to adult HIV care) and residential (from institutional to independent living).[2,11] This convergence has received almost no research attention internationally, yet it carries psychological, social, and structural consequences that clinical transition frameworks alone do not capture.

Mental health and psychosocial wellbeing are increasingly recognized as central to HIV transition outcomes. Orth and van Wyk's qualitative study of mental wellness among adolescents living with HIV in South Africa identified peace, hope, resilience, and emotional balance as core themes in young people's own conceptualizations of wellness,[4] challenging deficit-based frameworks and pointing toward asset-based approaches that begin with what young people value rather than clinical thresholds they must meet. These findings are particularly salient in LMIC contexts, where the psychosocial burden of growing up with HIV — navigating disclosure, stigma, and uncertainty — is often amplified by structural factors including poverty, limited social safety nets, and restricted access to mental health services.

3. METHODS

3.1 Study Design and Setting

This qualitative photovoice study was conducted at two sites in Karnataka, India, representing participants with contrasting urban and care contexts: Bengaluru (metropolitan, family-based and institutional care) and Belgaum (semi-urban, institutional care). The study, coordinated by local civil society organizations, YRGCARE and RISHI Foundation, is part of a larger parent mixed-methods study (IRB No. IRB00033960 at Johns Hopkins) and builds on prior CBPR partnership work conducted with these communities.[8] This parent study examines how YLHIV in India perceive and experience transition from pediatric to adult care using participatory and human-centered methods, with a goal to co-develop a culturally relevant transition readiness tool grounded in the lived experiences and priorities of YLHIV.

The selection of two contrasting sites for the photovoice component of the parent study was purposive, designed to elicit perspectives from YLHIV growing up in different care contexts that produce divergent transition pathways. Bengaluru participants were older (above 18 years), and a mix with some residing with biological family members or CCIs and receive HIV care through community-based clinical infrastructure; Belgaum participants, we minors, who reside primarily in residential child care institutions (CCIs) where housing, healthcare coordination, and psychosocial support are provided within the institutional environment. This contrast enables exploration of how care setting shapes the experience of transition.

3.2 Participants and Recruitment

Sixteen participants were recruited from youth who completed a cross-sectional survey (Aim 1 of the parent study) and indicated interest in photovoice. Purposive sampling ensured variation in age, gender, and care setting: 8 in Bengaluru (6 completed FGD) and 8 in Belgaum (all completed FGD). Ages ranged from 13 to 22 years. Six participants identified as female and ten as male. One Bengaluru participant could not be reached for the focus group discussion despite multiple contact attempts. Demographic characteristics and study completion details for each participant are presented in Table 1.

The Aim 1 survey was an interviewer-administered, cross-sectional instrument completed at the YRGCARE and RISHI Foundation sites covering sociodemographic information, parental vital and HIV

status, current and prior childcare institution residence, educational and employment status, and HIV-related stigma assessed with the Pune-HIV Stigma Scale (PHSS), a 12-item adaptation of the 40-item Berger Health Stigma Scale validated among young people with HIV in India.[3] The PHSS scores four subscales (negative self-image, disclosure concerns, personalized stigma, and public attitudes) on a 4-point Likert scale (total range 12–48). Among the photovoice cohort (n=14), PHSS total scores ranged from 17 to 33 (mean 26.7, SD 4.9), with comparable site distributions (Belgaum mean 26.9, SD 5.3; Bengaluru mean 26.5, SD 4.9). Cohort demographics, care history, and stigma distributions are summarized in Table 1.

3.3 Ethical Considerations

The study was approved by the Institutional Review Board of the Johns Hopkins Bloomberg School of Public Health (IRB No. IRB00033960), the YRG CARE Institutional Review Board, and the University of Washington (UW IRBSTUDY 00025166). Adult participants (aged 18 years and above) provided written informed consent; minor participants received written parental permission and provided written assent. Consent, parental permission, and assent forms were available in English and Kannada. All study activities were conducted in private settings. Participants were trained in ethical photography practices, including obtaining permission before photographing other individuals, protecting the privacy of subjects, and ensuring personal safety while taking photographs. The right to refuse to participate in any or all parts of the discussion was made clear at the beginning of each session. Referral pathways to counseling and psychosocial support were established at both sites to address any emotional distress that arose during participation.

3.4 Reflexivity and Positionality

In keeping with established guidance for qualitative research and community-based participatory work, the author reflected on her positionality throughout the study. The author is a Master of Public Health student at the University of Washington School of Public Health. She was born and raised in Bangalore through her teenage years and is fluent in Kannada, which enabled her to co-facilitate the focus group discussions in participants' first language and to participate directly in transcription and

translation. This linguistic and cultural fluency shaped her access to idiomatic expressions, culturally embedded references, and locally specific norms and taboos that informed both the conduct of the sessions and the interpretation of the transcripts. At the same time, her current training in a U.S. institution and her position as a member of an international research team introduced a degree of outsider distance from participants' day-to-day contexts, particularly for participants in institutional care in Belgaum.

Three sets of power dynamics were considered during the study. First, dynamics between research institutions (the academic and clinical organizations underwriting the study) and participants were mitigated through informed consent and assent processes, locally embedded coordination through YRGCARE and RISHI Foundation, and clear signaling that participation and non-participation carried equivalent standing. Second, dynamics between research institutions and peer counselors were addressed by positioning peer counselors as co-facilitators rather than data collectors and by ceding lead facilitation to peer counselors in the second focus group discussion, in keeping with CBPR principles of shared leadership. Third, dynamics between peer counselors and participants were attended to by selecting peer counselors with shared lived experience and by encouraging participants to direct the pace and depth of their own disclosures.

Translation choices were made collaboratively rather than unilaterally. The author conducted the focus group sessions in English and Kannada, worked alongside trained Kannada transcribers, and resolved idiomatic uncertainties through team discussions with peer counselors. The author acknowledges that her insider familiarity with the language, culture, and social norms of the study setting likely strengthened the cultural specificity of the analysis. Coding decisions were therefore subjected to systematic inter-coder reliability review and consensus calibration to mitigate single-coder bias.

3.5 Data Collection Procedures

3.5.1 Orientation Sessions (March 15-21, 2026)

All participants attended structured orientation sessions introducing photovoice methodology[9] using age-appropriate language. Sessions were primarily conducted in groups, with one participant

receiving individual orientation due to inability to attend the group session. Facilitators consisted of two peer counselors and this author. Peer counselors were young adults living with HIV trained through the partner consortium's I'm Possible Fellowship—a peer-led differentiated service delivery model implemented across Karnataka and Tamil Nadu that prepares fellows aged 18–27 years to provide informational, emotional, and affirmational support to younger YLHIV under the supervision of program staff.[16] Their shared lived experience with HIV and their structured training in peer mentorship enabled the development of trust and psychological safety with participants during the discussions.[8] Facilitators presented a PowerPoint covering: (a) the purpose of the study and the concept of transition (framed as movement from pediatric to adult HIV care and from dependent to independent life roles); (b) how photographs can communicate complex feelings and experiences that are difficult to articulate verbally; (c) examples from prior photovoice studies demonstrating how images represent both concrete realities and abstract concepts, including work with Ugandan YLHIV;[15] (d) ethical photography practices (obtaining permission, protecting privacy, safety while taking pictures); and (e) a guided practice exercise in which participants viewed a sample photograph and wrote captions interpreting its meaning and relevance to transition.

3.5.2 Photography Assignment

Following the orientation, participants were given one week to photograph responses to the prompt: 'What has your experience of growing up been like, and what are you worried about for your future?' Participants were encouraged to take multiple photographs from their daily environments and select the images they felt most strongly represented in their experiences. For each photograph, they prepared written captions (in English in Bengaluru, and in Kannada in Belgaum) describing the image's meaning and relevance to their lives. The one-week timeline was selected to allow sufficient observation and reflection while maintaining engagement and momentum.

3.5.3 Focus Group Discussions (March 18 and 28, 2026)

Focus group discussions were conducted at each site on March 18, 2026 (Bengaluru, n=6) and March 28, 2026 (Belgaum, n=8). Sessions lasted 90 to 120 minutes. The first session was co-facilitated by the author and peer counselors from RISHI Foundation. In the second session, peer counselors took

the lead facilitation role with the author providing support, reflecting CBPR principles emphasizing partnership and local leadership. Participants shared one to two selected photographs with the group.

Facilitators used the SHOWeD framework[9] to guide reflection:

- What do you ***S***ee here?
- What is really ***H***appening here?
- How does this relate to ***O***ur lives?
- ***W***hy does this condition ***E***xist?
- What can we ***D***o about it?

Following the photo-sharing segment, discussions continued with a semi-structured guide addressing four thematic areas: (1) Growing Up and Becoming Independent, (2) Support from Family, Friends, and Providers, (3) Getting Ready for Adult Care and Independent Living, and (4) Ideas for Better Support. All discussions were audio-recorded with participants' written, IRB-approved consent and verbal consent.

3.6 Data Management and Transcription

Audio recordings were transcribed verbatim in English and/or Kannada by trained transcribers and translated into English by the author and verified by peer counselors. All transcripts were reviewed against audio recordings for accuracy, with particular attention to pauses, emotional emphasis, and group dynamics. During translation, idiomatic phrases and culturally embedded terminology were translated for conceptual meaning rather than literal wording, with uncertainties discussed and settled with team. All transcripts and associated photographs were uploaded to Dedoose (v9.x), a web-based qualitative data analysis platform that supports collaborative coding and inter-coder reliability testing.

3.7 Coding and Inter-Coder Reliability

To ensure analytical rigor, two members of the research team (AS and SS) independently coded all focus group discussion transcripts using a finalized codebook in Dedoose. The author served as the first coder.

Following a systematic consensus meeting, coding decision rules were established for each code and documented in a shared ICR Protocol. The codebook was restructured into three parent domains (Transition/Independence; Interpersonal and Community Role in Transition; Recommendations to Facilitate the Transition Process) reflecting a socioecological framework consistent with the social determinants of adolescent health.[1] Five inductive codes were formally defined and calibrated. Both transcripts were re-coded in full following the restructured codebook.

A formal ICR test was then conducted using Dedoose's Testing Center (62 excerpts, taken May 14, 2026), yielding a Pooled Cohen's Kappa of 0.66. The research team undertook targeted consensus calibration on the three codes that showed the lowest agreement in the formal test (Goals and Targets, Familial Duty, and Fears about Safety and Enforcement). Decision rules for these codes were refined and documented in the ICR Protocol, and all remaining discrepancies were resolved through discussion until full consensus was reached. Any remaining disagreements were resolved through discussion and consensus, with rationale documented in the ICR Protocol. The final codebook structure can be found in Appendix 1.

3.8 Analytic Approach

Coded data were analyzed thematically using a hybrid deductive-inductive approach. Deductive codes derived from the SHOWeD framework[9] and the literature on adolescent transition,[1,2,5,14] while inductive codes emerged from close reading of transcripts and were formalized through the consensus process. Themes were developed at the parent domain level and refined through iterative review of coded excerpts within each subtheme. Where appropriate, findings are illustrated with participant quotes and references to photographs, with identifying information removed to protect participant confidentiality.

TABLE 1: PARTICIPANT DEMOGRAPHICS AND STUDY COMPLETION

Characteristic	n	%
District		
Bangalore/Kolar	*8*	*50*
Belgaum	*8*	*50*
Age		
13–15	*3*	*19*
16–17	*6*	*38*
18–19	*2*	*13*
20–22	*5*	*31*
Gender		
Male	*10*	*62.5*
Female	*6*	*37.5*
Care setting		
Family-based	*5*	*31*
Institutional	*11*	*69*
Orientation status		
Completed (Orientation)	*16*	*100*
Completed (Photovoice+FGD)	*14**	*87.5*
Place of residence (n=14)		
Rural	*8*	*57*
Urban	*6*	*43*

Parental status (n=14)		
Both parents alive	*3*	*21*
Single orphan – father deceased	*5*	*36*
Single orphan – mother deceased	*1*	*7*
Double orphan – both parents deceased	*5*	*36*
Educational engagement (n=14)		
Currently studying	*12*	*86*
Currently studying in person	*10*	*71*
Currently studying by correspondence/online	*2*	*14*
Employment (n=14)		
Currently employed (all Bengaluru)	*4*	*29*
Years in CCI		
Current residents (n=7), median (range)	*2 (1–14)*	*—*
Prior residents (n=4, Bengaluru), median (range)	*15 (11–16)*	*—*
HIV-related stigma (PHSS total, n=14)		
Mean (SD)	*26.7 (4.9)*	*—*
Range	*17–33*	*—*
Belgaum site (n=8): mean (SD)	*26.9 (5.3)*	*—*
Bengaluru site (n=6): mean (SD)	*26.5 (4.9)*	*—*

**One Bengaluru participant unable to be reached for FGD; and another was unable to attend the session on the designated date.*

TABLE 2: THEMATIC STRUCTURE—PARENT DOMAINS, SUBTHEMES, AND CORRESPONDING CODES

Parent Domain	***Subtheme***	***Key Codes***	***# of Applications***
Transition/Independence	*Meaning of growing up with HIV*	*Differential Experience (HIV/Institutional); Meaning of Growing Up; Age & Responsibility Onset*	*49 + 40 + 33 = 122*
Transition/Independence	*Independence concept and actions*	*Independence (Concept & Meaning); Independence (Actions & Behaviors); Familial Duty*	*25 + 40 + 14 = 79*
Transition/Independence	*Transition readiness*	*Transition Readiness (Knowledge & Skills); Goals & Targets; Barriers to Transition; Facilitators of Transition*	*29 + 21 + 17 + 22 = 89*
Transition/Independence	*Perceptions of transition*	*Perceptions of Transition; Stress about Growing Up*	*36 + 10 = 46*
Interpersonal & Community Role	*Support systems*	*Key Sources of Support; Role of Social Network in Transition*	*48 + 27 = 75*
Interpersonal & Community Role	*Facilitators and barriers to self-care*	*Facilitators of Self-Care; Barriers to Self-Care; Stigma & Coping*	*20 + 15 + 5 = 40*

Interpersonal & Community Role	*Safety and institutional concerns*	*Fears about Safety & Enforcement**	*17*
Recommendations to Facilitate	*Youth-generated suggestions*	*Action & Change Orientation; Peer/Community Programs; Tools & Resources; Clinic/System Improvements; HIV-Specific Health Education*	*12 + 13 + 6 + 5 + 0 = 36*
INDUCTIVE CODES (cross-cutting)	*Inductive themes*	*Familial Duty; Goals & Targets; Fears about Safety; Stress about Growing Up; Stigma & Coping; HIV-Specific Health Education; Photovoice Impressions*	*14 + 21 + 17 + 10 + 5 + 0 + 4 = 71*

4. RESULTS

4.1 Overview of Findings

The analysis yielded 29 codes across three parent domains — Transition/Independence, Interpersonal and Community Role in Transition, and Recommendations to Facilitate the Transition Process — and seven inductive codes that emerged during analysis. Across 327 coded excerpts (Bengaluru n=101; Belgaum n=226), participants articulated multidimensional perspectives on what it means to grow up with HIV, what makes transition feel possible or impossible, and what support they need to navigate the move toward independent adulthood. Key findings are presented below, organized by domain. A comprehensive summary of themes, subthemes, and corresponding codes is presented in Table 2.

4.2 Domain 1: Transition and Independence

Meaning of growing up with HIV

The code ‘Differential Experience – HIV/Institutional Context’ (49 applications, the highest-frequency code) captured participants’ awareness that growing up with HIV — and for Belgaum participants, within a residential institution — shaped adolescence in ways that distinguished them from peers. Daily medication, hospital visits, and the visibility of HIV-related markers affected peer relationships, school experience, and self-concept. Participants identified age 18 as the threshold at which adult expectations crystallize, captured by ‘Age and Responsibility Onset’ (33 applications): managing one’s own medication, earning income, making decisions, and assuming family obligations. Critically, participants emphasized that education about HIV, health management, and life responsibilities should begin from age 12, well before the formal transition threshold.

This bandage shows that even a small act of care can protect and heal, reminding us that if we are suffering from a disease, kindness means taking precautions and not risking others' health by spreading infection.

-Bengaluru Participant

Independence as relational capacity

Participants conceptualized independence not as individual autonomy but as the capacity to fulfill obligations to family and care for others. The inductive code ‘Familial Duty as Part of Transition’ (14 applications) captured this orientation: financial independence, career success, and adult competence were framed as means of repaying parents, providing for siblings, and securing family stability — reflecting collectivist values in which individual achievement is defined through its service to the family unit.

“When we grow up and start working, our parents have raised us. We don’t want to leave them. We should look after them well. After growing up, we should take blessings from parents.”

- Belgaum FG Participant

Multidimensional transition readiness

Conceptualizations of transition readiness extended far beyond the biomedical domain. While HIV knowledge, medication management, and provider communication were identified as important (29 applications, ‘Transition Readiness – Knowledge & Skills’), participants equally emphasized educational readiness, employment readiness, psychological readiness, and housing and social readiness. The

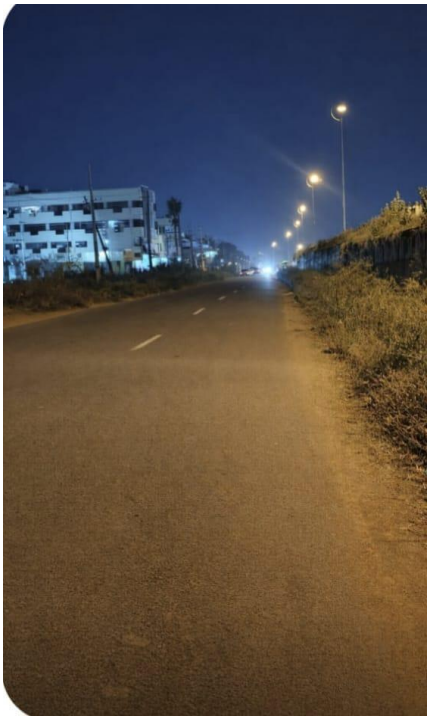
inductive code ‘Goals and Targets as Part of the Transition Process’ (21 applications) captured the degree to which participants linked clinical transition to a broader life trajectory: completing schooling, earning a salary, and providing for family were described as interdependent steps, not separate domains.

I will attain my goals no matter the obstacles that come in my way. No matter what people say about me, I believe I will attain my goals. I will reach my aims.

-Belgaum Participant

Perceptions of transition and the weight of growing up

The concept of ‘peace’ emerged as central to participants’ conceptualization of successful adulthood. Participants repeatedly identified psychological wellbeing and mental health as foundational to managing HIV and achieving independence. The inductive code ‘Stress about Growing Up’ (10 applications) captured the converse: anxiety, pressure, and the difficulty of navigating new expectations without adequate support.



Surrounded by a building and limited soil space, the plant adapts to its environment. It shows how surroundings influence growth and well-being.

In this picture, I have captured a beautiful scene from nature. When I saw this view, I felt very happy. It reminded me of how peaceful and meaningful nature can be.

In our daily busy lives, we often forget to notice such small but beautiful moments. This picture shows how important it is to pause and appreciate the beauty around us.

Through this, I understand that nature teaches us patience, calmness, and balance. It also reminds me to stay positive and value simple things in life.

-Bengaluru Photovoice Caption

4.3 Domain 2: Interpersonal and Community Role in Transition

Support systems

Support systems centered on family members in Bengaluru and on institutional caregivers , particularly the hostel in-charge referred to as ‘Madam’, in Belgaum. Healthcare providers, counselors, and peers served as secondary support. The code ‘Key Sources of Support’ (48 applications) captured participants’ consistent identification of these primary attachment figures. The role of ‘Madam’ in Belgaum was particularly salient: described as caregiver, disciplinarian, confidant, and proxy parent, she occupied a singular attachment role whose anticipated loss at discharge was a source of significant anticipatory grief.

Surrounded by a building and limited soil space, the plant adapts to its environment. It shows how surroundings influence growth and well-being.

-Bengaluru Participant

Stigma, disclosure, and help-seeking

"The difficulties that come as we grow; we shouldn't share them with anyone. We should swallow our difficulties and keep going."

-Belgaum FGD Participant

Stigma and disclosure anxiety constrained help-seeking even where supportive relationships existed. Fear of unintended disclosure or judgment limited whether participants felt comfortable discussing HIV-related challenges, even with trusted figures. These patterns reflect the multidimensional stigma framework operationalized in the Aim 1 PHSS data,[3] in which enacted, anticipated, and internalized stigma each contribute distinctly to YLHIV experience. The inductive code 'Stigma and Coping' (5 applications) documented coping strategies including non-disclosure, cognitive reframing, spiritual coping, and stoicism, with internalizing strategies often masking rather than resolving emotional distress.

Safety fears and the grief of institutional departure

”A sheep without a shepherd is lost & will go anywhere & do anything & will put its life in danger. So, how a sheep needs a shepherd we need a shepherd in our life. Otherwise, like the sheep we will go anywhere, & get spoilt and we might lose our life.”

– Belgaum Photovoice caption

Participants in institutional care described anxieties unique to their context. The inductive code ‘Fears about Safety and Enforcement’ (17 applications) encompassed two subtypes: legal and enforcement fears (anxiety about labor laws, fines, and accidents) and safety-through-parental-loss fears, in which participants framed safety behaviors as protecting parents from grief rather than themselves from harm. Most poignantly, Belgaum participants described anticipatory grief about leaving the hostel and their Madam. The collective utterance “No one will come and tell us, “Articulated in different forms across the focus group discussion, captured perceptions of future unsupervised vulnerability , an anticipation not of freedom but of loss of care, attention, and community.

4.4 Domain 3: Recommendations to Facilitate the Transition Process

Participants generated specific recommendations across five code categories (36 total applications). Peer and Community Programs (13 applications) captured enthusiasm for peer mentorship models connecting older YLHIV with younger ones. Action and Change Orientation (12 applications) reflected problem-solving framing, with proposals for community education through drama, video, and

local awareness campaigns. Tools and Resources (6 applications) and Clinic/System Improvements (5 applications) captured concrete suggestions for transition materials and clinic-level changes. Notably, the code 'HIV-specific Health Education' accumulated zero applications in the coded transcripts — participants did not describe receiving structured HIV education despite consistently emphasizing it should begin from age 12. This gap between perceived need and current provision represents a clear opportunity for intervention design.

4.5 Photovoice as a Methodological Window

Throughout the focus group discussions, participants used photographs to communicate experiences and emotions difficult to articulate verbally. Images of empty cupboards became metaphors for unfulfilled goals; photographs of long roads represented the journey of growing up; pictures of plants conveyed both aspiration and recognition of support. These visual metaphors carried analytic weight, revealing how participants conceptualized their lives rather than merely what they reported about them, consistent with documented strengths of photovoice across HIV research contexts.[9,14,15] The photographs and captions also altered discussion dynamics: participants who were quieter in verbal exchanges often took the lead when discussing their own images, suggesting the visual frame provided a less threatening pathway into sensitive topics.

5. DISCUSSION

This photovoice study reveals that the transition from pediatric to adult care is fundamentally multidimensional, encompassing not only clinical handover but also residential stability, educational and employment pathways, psychological wellbeing, and the assumption of familial responsibilities. The most actionable implication for program design concerns timing: although participants identified age 18 as the formal threshold of responsibility, they emphasized that meaningful preparation should begin from age 12. Current transition protocols, which typically concentrate intervention in the 12–24 months preceding transfer, may therefore be poorly timed. Transition preparation should be reconceptualized as an

extended developmental process beginning in early adolescence, with intensifying support as the young person approaches adulthood.[1,2] Equally notable was participants' framing of successful adulthood in terms of peace, stability, and mental health rather than biomedical outcomes, pointing to a holistic model in which psychological wellbeing anchors sustained engagement in care. This aligns with Orth and van Wyk's documentation of mental wellness discourses among South African adolescents living with HIV,[4] in which peace, hope, and emotional balance emerged as core themes, suggesting youth-centered conceptualizations of wellbeing may share important commonalities across LMIC settings.

For participants in institutional care in Belgaum, these challenges were compounded by a simultaneous residential transition that the HIV transition literature has largely overlooked.[2,11] The anticipatory grief expressed by Belgaum participants — captured in the collective utterance "No one will come and tell us" — reflects not clinical unreadiness but the mourning of institutional protection and relational community. These findings extend prior documentation of psychosocial wellbeing among children in Indian HIV care homes[11] and of emotional dynamics in South African HIV residential settings,[7] establishing that the relational structures created by residential childcare have a life of their own whose dissolution at discharge constitutes a substantial life event that intersects with, and complicates, the clinical transition. Transition support for childcare institutions must include structured exit planning, post-discharge follow-up, deliberate maintenance of community connection, and explicit attention to the affective dimensions of leaving.

The finding that independence is conceptualized as relational rather than individual, the capacity to fulfill obligations to family rather than achieve autonomous self-management, challenges assumptions embedded in many Western-derived transition frameworks.[1,2] This collectivist orientation, consistent with broader scholarship on South Asian adolescent development,[1] has direct practical implications: interventions focused exclusively on individual biomedical self-management will miss what matters most to participants. Programs should integrate financial literacy, education support, and family-oriented goal setting, recognizing responsibilities to others as legitimate transition objectives. Similar arguments have been made from the Ugandan context,[13] reinforcing the need for transition frameworks developed within rather than exported to low- and middle-income settings.

Stigma emerged as a constraint on help-seeking even where support relationships existed. Participants' coping responses such as non-disclosure, cognitive reframing, spiritual coping, and stoicism, align with Marbaniang and colleagues' multidimensional stigma framework,[3] and the PHSS scores observed in this cohort (mean 26.7 of 48, SD 4.9) reflect moderate stigma burden across both sites. A critical implication follows: transition programs cannot rely on YLHIV proactively seeking help, and must instead build structured, low-disclosure pathways for support. Peer mentorship models, which participants themselves endorsed and which are being developed within this study's partner consortium,[16] may be particularly effective because shared YLHIV identity reduces the disclosure burden.

The photovoice methodology proved effective at surfacing dimensions of transition experience inaccessible through standardized instruments alone. As described in the Results, participants' visual metaphors revealed how they conceptualized their lives rather than simply reported on them, consistent with documented strengths of photovoice across HIV research settings.[9,14,15] The integration of CBPR principles — peer counselors as co-facilitators, iterative codebook development, and community partnership involvement — strengthened validity and reflected ethical commitments to youth partnership. Prior CBPR work with these communities[8] established the relational infrastructure that made the present study possible, illustrating the importance of long-term community engagement in producing rigorous, ethical research with vulnerable populations.

Several policy and practice implications follow from these findings. Transition preparation should begin from approximately age 12, with developmentally-staged interventions across health, education, employment, and psychosocial domains. YLHIV in institutional care require structured exit planning that addresses the relational and affective dimensions of leaving. Peer mentorship programs connecting older YLHIV with younger ones show particular promise for addressing stigma-related barriers.[16] Transition tools and protocols should be developed with YLHIV using CBPR principles rather than imported from high-income contexts,[1,2] and India's national HIV program[6,12] should consider an adolescent-specific transition protocol reflecting the role of CCIs, collectivist family structures, and stigma's effect on help-seeking. Existing clinic-administered transition tools,[17] while valuable for improving HIV self-management, do not address the full scope of multidimensional readiness that participants described.

This study has several strengths. The use of CBPR principles, with peer counselors from partner organizations co-facilitating focus group discussions, reflects authentic youth partnership rather than tokenistic participation. The photovoice methodology surfaced embodied, complex experiences not captured by standardized instruments, and the systematic approach to inter-coder reliability, with documented decision rules and formal Dedoose Testing Centre assessment, strengthens analytical confidence.

Limitations include the small sample (N=14 completing FGDs) and restricted geographic scope (two sites in one Indian state), which limit generalizability. The formal inter-coder Pooled Cohen's Kappa of 0.66 corresponds to substantial rather than near-perfect agreement; the team addressed this through targeted calibration and resolving disagreements by consensus with rationale documented in the ICR Protocol. Finally, while photovoice is participatory in data generation, interpretation was conducted by the research team rather than jointly with participants; a member-checking session is planned to address this limitation.

6. CONCLUSION

This photovoice study with youth living with HIV in India demonstrates that transition from pediatric to adult care is a multidimensional process encompassing education, employment, housing, psychosocial wellbeing, and relational responsibilities — not a discrete clinical event. Independence is conceptualized relationally, with psychological peace and the capacity to care for family as foundational. Findings argue for developmentally-staged transition preparation beginning in early adolescence, structured exit planning and post-discharge follow-up for youth leaving institutional care, peer-mentorship grounded in shared lived experience, and integrated attention to stigma and disclosure. The photovoice methodology, by enabling communication through visual narrative and collective dialogue, surfaced priorities and experiences that standardized instruments miss. These findings will inform the development of a comprehensive, multidimensional transition readiness tool grounded in the lived experiences of YLHIV in low- and middle-income country settings.

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Appendix 1: COMPLETE CODEBOOK

Type key: Deductive = specified a priori from FGD guide; Inductive = emerged from participant data during analysis.

Parent Domain	Code Name	Type	Description	Inclusion Criteria	Exclusion Criteria	Example from FGD Data
PARENT DOMAIN: TRANSITION / INDEPENDENCE						
Transition / Independence	**Meaning of Growing Up**	**Deductive**	Participant's personal or social understanding of what it means to grow up, including milestones, responsibilities, and identity changes.	• Reflections on growing up as a developmental or social process • Descriptions of milestones, rites of passage, or role changes associated with adulthood • Affective, metaphorical, or narrative framings of growing up	• Specific age thresholds without reflective meaning → Age & Responsibility Onset • Future-oriented attitudes about the healthcare transition → Perceptions of Transition • Specific goals tied to growing up → may co-code with Goals & Targets	"Really happening means a plant is having a healthy life... they just give a memory and just they get into vanish, means they will leave us."
Transition / Independence	**Age & Responsibility Onset**	**Deductive**	Perceived age at which young people begin to assume greater personal responsibility; norms and expectations around this transition.	• References to a specific age (e.g., 18) as a threshold for responsibility • Statements about age-linked expectations from family, institution, or society • Comparisons of responsibility before and after a	• General reflections on growing up without age reference → Meaning of Growing Up • Emotional stress about the pace of change → Stress about Growing Up	"When I was playing and having fun — those times make me happy. But there's sadness too — all this time we were watching sports, and now suddenly we have to pick up books."

Parent Domain	Code Name	Type	Description	Inclusion Criteria	Exclusion Criteria	Example from FGD Data
				perceived age threshold	• Recommendations for when education should begin → HIV-Specific Health Education or Recommendations domain	
Transition / Independence	**Independence – Concept & Meaning**	**Deductive**	How participants define and conceptualize independence in the context of their own lives, including emotional, social, and practical dimensions.	• Definitions or descriptions of what independence means to the participant • Contrasts between dependence and independence in the participant's own framing • Relational or collectivist understandings of independence (e.g., independence as capacity to support family)	• Specific behaviors that enact independence → Independence – Actions & Behaviors • Obligation to family as driver of independence → Familial Duty as Part of Transition • General descriptions of growing up without definitional content → Meaning of Growing Up	"Earlier we used to play, have a lot of fun. Gradually, in 8th, 9th, 10th grade — the desire arose: we need to study, we need to pass, we need to do this, we need to do that. We feel that if we do it this way, things will be good, we can grow more, grow even higher."
Transition / Independence	**Independence – Actions & Behaviors**	**Deductive**	Specific behaviors or activities participants currently engage in that reflect growing autonomy (e.g., managing medications,	• Descriptions of self-management behaviors (medication management, scheduling appointments)	• Conceptual definitions of independence → Independence – Concept & Meaning	"be independent and get confidence and in a way they left me to travel alone and know about the outside world and to feel

Parent Domain	Code Name	Type	Description	Inclusion Criteria	Exclusion Criteria	Example from FGD Data
			making appointments, decision-making).	• Financial or logistical independence behaviors (managing money, cooking, transport) • Decision-making behaviors performed without caregiver assistance	• Factors that support self-care behaviors → Facilitators of Self-Care • Behaviors recommended for others → Recommendations domain	that outside world and how it is and same time they are building my confidence in giving little tasks and helping me to grow in both the sides like growing mentally and financially also, to build my confidence and to be independent when I go outside."
Transition / Independence	**Differential Experience – HIV / Institutional Context**	**Deductive**	Ways in which growing up with HIV or in a childcare institution shapes the experience of adolescence differently compared to peers without these experiences.	• Comparisons between the participant's experience and that of peers without HIV or institutional care • Descriptions of how HIV status or institutional setting meaningfully shapes daily life, relationships, or future • Accounts where HIV or institutional context is the explicit driver of a	• Incidental HIV mention where HIV does not shape the experience described → do not add this code (see ICR Rule 1) • HIV-specific stigma or disclosure anxiety → Stigma and Coping • Institutional departure grief → Perceptions of Transition or Fears about Safety and Enforcement	"We enjoy ourselves. Life becomes like a change. We must take medicines properly — if we take even one medicine properly, we can conquer the world."

Parent Domain	Code Name	Type	Description	Inclusion Criteria	Exclusion Criteria	Example from FGD Data
				different experience		
Transition / Independence	**Transition Readiness – Knowledge & Skills**	**Deductive**	Health literacy and practical skills perceived as necessary before transitioning, including understanding HIV, communicating with providers, managing medications, and scheduling appointments.	• Identification of knowledge or skills participants believe are needed before transition • Self-assessments of readiness for adult care or independent living • Descriptions of what young people should know or be able to do before transitioning	• Behaviors already enacted → Independence – Actions & Behaviors • Recommendations for transition preparation programs → Recommendations domain • Knowledge gaps that function as barriers → Barriers to Transition	"We need to do a job. We'll need to get a room(Rent a place) and we get all the things needed for living there, we need to learn about all of it from now."
Transition / Independence	**Barriers to Transition**	**Deductive**	Structural, psychosocial, or informational factors that make the move to adult care more difficult (e.g., lack of information, loss of trusted providers, stigma, unfamiliar systems).	• Identification of specific obstacles to the transition (informational, relational, structural) • Descriptions of what makes the transition difficult, scary, or poorly supported • Loss of trusted providers, unfamiliarity with adult systems, or lack of preparation	• Barriers to self-care that are not transition-specific → Barriers to Self-Care • Stigma as a barrier → may co-code with Stigma and Coping • Safety and enforcement fears → Fears about Safety and Enforcement	"Some people keep their distance because of HIV. So, they should take counseling. For whom? People who keep their distance. They should be told in homes, schools, and colleges not to do that."

Parent Domain	Code Name	Type	Description	Inclusion Criteria	Exclusion Criteria	Example from FGD Data
Transition / Independence	**Facilitators of Transition**	**Deductive**	Conditions or supports that ease the transition to adult care, such as gradual handover, peer support, provider continuity, or preparation programs.	• Identification of factors that have made or would make the transition easier • Descriptions of preparation, support structures, or relationships that facilitate the move • Positive features of the transition process or of adult care settings	• Facilitators of self-care (not transition-specific) → Facilitators of Self-Care • Participant recommendations for what programs should do → Recommendations domain • Support persons identified without transition framing → Key Sources of Support	“Education is everything. Whatever activities they give in school, we should do those. We should start thinking about what we want to become. If someone has done a certain kind of work, ask them about it — how they do it, what benefit it has. And we should try an emulate it and try to live a good life.”
Transition / Independence	**Perceptions of Transition**	**Deductive**	Participants' feelings, attitudes, fears, and expectations about moving from pediatric/adolescent care to adult healthcare settings.	• Evaluative or affective language about the transition to adult care • Anticipatory feelings (fear, excitement, ambivalence) about moving to adult services • Expectations or imaginings of what adult care will be like	• Future-oriented statements without evaluative or affective content → do not apply • Grief about institutional departure that centers on loss of community → also code Differential Experience • Stress about growing up generally (not transition-specific)	"After we leave this hostel and go home, our parents will say 'Let them be free.' We'll think that's real freedom, and our attention won't go toward studies."

Parent Domain	Code Name	Type	Description	Inclusion Criteria	Exclusion Criteria	Example from FGD Data
					→ Stress about Growing Up	
Transition / Independence	**Familial Duty as Part of Transition**	**Inductive**	Independence conceptualized as relational obligation — the drive to achieve self-sufficiency in order to care for, repay, or fulfill duties toward named family members; reflects a collectivist rather than individualistic model of adulthood.	• Participant frames independence as means to fulfill obligation to a named family member • Reciprocal duty logic: participant must give back, repay, or care for parents or siblings • Adulthood defined as capacity to contribute to family wellbeing	• General mention of family support without reciprocal obligation logic → Key Sources of Support • Parental wishes for participant without participant taking on a duty → Perceptions of Transition • Collectivist statements not anchored to a specific family obligation → do not apply	“When we grow up and start working, our parents have raised us. We don’t want to leave them. We should look after them well. After growing up, we should take blessings from parents.”
Transition / Independence	**Goals & Targets as Part of the Transition Process**	**Inductive**	Specific goals, aspirations, or targets — educational, occupational, financial, or personal — explicitly linked by the participant to the process of growing up, becoming independent, or transitioning to adult care.	• Goals explicitly framed as part of what it means to grow up or transition • Educational or occupational targets connected to assumption of adult roles • Goal-oriented metaphors interpreted in relation to the transition journey	• Free-standing aspirations without explicit link to growing up or transition → do not apply • Current preparation behaviors → Independence – Actions & Behaviors • Recommendations for programs →	"this cupboard is lifeless... inside it there is a goal, we need to reach that goal"

Parent Domain	Code Name	Type	Description	Inclusion Criteria	Exclusion Criteria	Example from FGD Data
					Recommendations domain	
Transition / Independence	**Stress about Growing Up**	**Inductive**	Expressions of emotional stress, anxiety, overwhelm, or psychological burden specifically associated with growing up — including the accumulation of new responsibilities, grief about developmental change, and the emotional weight of navigating adulthood without adequate preparation.	• Emotional or somatic expressions of burden tied to accumulating responsibilities • Grief, sadness, or anxiety about leaving behind familiar structures or stages of life • Psychological difficulty of navigating growing up with HIV alongside developmental change	• Evaluative statements about the transition without affective expression → Perceptions of Transition • Specific safety or enforcement fears → Fears about Safety and Enforcement • Stigma-related distress → Stigma and Coping	"When I was playing and having fun, those times make me happy. But there's sadness too, all this time we were watching sports, and now suddenly we have to pick up books."
Transition / Independence	**Fears about Safety and Enforcement**	**Inductive**	Fears and anxieties related to personal safety, legal enforcement, or vulnerability from reduced institutional or parental oversight; includes legal/enforcement fears (fines, police, legal thresholds) and safety-through-parental-loss fears (unsafe behavior framed as risk of causing parental grief).	• Legal/enforcement fears: legal thresholds, fines, penalties, official enforcement • Safety-through-parental-loss: safety behavior framed in terms of consequences for parents/caregivers • Anticipatory anxiety about navigating safety	• General growing-up anxiety without safety/enforcement reference → Stress about Growing Up • Institutional departure grief centered on loss of community → Perceptions of Transition • HIV-specific legal or disclosure fears → Stigma and	" if a sheep doesn't have a shepherd, it will go anywhere, do anything, and put its life in danger. Therefore, a sheep needs a shepherd. Similarly, in our life too, we need a guide. Otherwise, the sheep will go anywhere, and it will spoil things. There is a

Parent Domain	Code Name	Type	Description	Inclusion Criteria	Exclusion Criteria	Example from FGD Data
				without institutional or parental oversight	Coping or Differential Experience	possibility of losing our life.”
PARENT DOMAIN: INTERPERSONAL & COMMUNITY ROLE IN TRANSITION						
Interpersonal & Community Role in Transition	**Key Sources of Support**	**Deductive**	Identification of the primary people or entities (family, healthcare providers, counselors, friends, peers) who provide support for health and growing up.	• Naming of specific people or entities who provide health or developmental support • Descriptions of what kind of support a person or entity provides • Support relationships where HIV context is incidental, not the shaping factor	• HIV/institutional context shapes the support relationship → also code Differential Experience (see ICR Rule 1) • How the social network functions in transition specifically → Role of Social Network in Transition • Factors that facilitate self-care (not people) → Facilitators of Self-Care	"for me it's my brother who takes care of me... he knows my situation that I have HIV so he knows what to do and he is supporting me so that I be independent"
Interpersonal & Community Role in Transition	**Role of Social Network in Transition**	**Deductive**	How family members, friends, or peer mentors can support or accompany youth through the transition to adult care.	• Descriptions of how relationships specifically support the transition process • Accounts of social network members accompanying, preparing, or	• Identification of support persons without transition focus → Key Sources of Support • Participant-generated recommendations for peer programs	“family supports me financially and since I am only with my friends and if something happens to me then my friends will take care.”

Parent Domain	Code Name	Type	Description	Inclusion Criteria	Exclusion Criteria	Example from FGD Data
				facilitating transition • Peer or community roles in supporting movement to adult care	→ Peer/Community Programs • Self-care support not tied to the transition → Facilitators of Self-Care	
Interpersonal & Community Role in Transition	**Facilitators of Self-Care**	**Deductive**	Factors that make it easier for participants to take care of themselves, including emotional readiness, accessible care, and encouragement from others.	• Identification of supports, conditions, or internal resources that enable self-care • Emotional readiness, motivation, or psychological stability as self-care enablers • Accessible services, reminders, or practical supports that help participants manage health	• Transition-specific facilitators → Facilitators of Transition • Specific support persons → Key Sources of Support • Self-care behaviors themselves → Independence – Actions & Behaviors	"We need to play games too, study too, pay attention to music, songs, drama, poetry, listen to everything carefully."
Interpersonal & Community Role in Transition	**Barriers to Self-Care**	**Deductive**	Factors that make self-care more difficult, including stigma, family dynamics, mental health challenges, financial constraints, and limited access to services.	• Structural barriers to self-care (cost, distance, availability of services) • Relational or family-dynamic	• Barriers specific to the transition process → Barriers to Transition • Stigma-related barriers → may co-code with	"Everyone is so busy and they're passing like that by themselves and no one is noticing some... they're noticing only the pots, some... some

Parent Domain	Code Name	Type	Description	Inclusion Criteria	Exclusion Criteria	Example from FGD Data
				barriers to managing health • Mental health, emotional, or cognitive factors that impede self-care	Stigma and Coping • Safety/enforcement barriers → Fears about Safety and Enforcement	made things. But they did not notice the hard work of their behind, what hard work is there."
Interpersonal & Community Role in Transition	**Stigma and Coping**	**Inductive**	Experiences of HIV-related stigma (anticipated, perceived, or enacted) and the coping strategies youth employ in response, including non-disclosure, cognitive reframing, spiritual coping, and stoicism; captures how stigma shapes help-seeking, disclosure decisions, and healthcare engagement.	• Descriptions of HIV-related stigma in healthcare, family, school, or community settings • Fear of disclosure or active concealment of HIV status to avoid judgment • Coping strategies: non-disclosure, reframing, spirituality, stoicism, peer connection • Internalized stigma: shame or self-blame associated with HIV status	• Structural self-care barriers without stigma reference → Barriers to Self-Care • Formal discrimination without HIV-specific stigma → Differential Experience • Stigma-reduction program recommendations → Clinic/System Improvements or Peer/Community Programs	"The difficulties that come as we grow; we shouldn't share them with anyone. We should swallow our difficulties and keep going."
PARENT DOMAIN: RECOMMENDATIONS TO FACILITATE TRANSITION PROCESS						
Recommendations to Facilitate	**Action & Change Orientation**	**Deductive**	Participant ideas and calls to action emerging from their photos,	• Direct calls to action or change (what should	• Specific program or tool recommendations	"Programs can also be done through videos. Dramas can

Parent Domain	Code Name	Type	Description	Inclusion Criteria	Exclusion Criteria	Example from FGD Data
Transition Process			focused on what can be done to improve conditions for youth living with HIV.	happen, who should act) • Statements of what needs to change for youth to be better supported • Action-oriented framing emerging from photo discussions (SHOWeD 'D' question)	→ Peer/Community Programs or Tools & Resources • Health system recommendations → Clinic/System Improvements • Descriptions of current conditions without action orientation → other thematic codes	be shown, or the activities you've done can be replicated"
Recommendations to Facilitate Transition Process	**Peer / Community Programs**	**Deductive**	Ideas for peer-led, community-based, or mentorship programs that participants believe would improve support for young people navigating independence and healthcare.	• Recommendations for peer mentorship, peer support groups, or buddy systems • Ideas for community-based programs or events supporting YLHIV • Suggestions for involving other youth in transition support	• Health system or clinic-level recommendations → Clinic/System Improvements • Specific tools or materials → Tools & Resources • General calls to action without program specificity → Action & Change Orientation	"They can teach about work , which work, how to do it, how much effort to put in, how to lead life."
Recommendations to Facilitate Transition Process	**Tools & Resources**	**Deductive**	Specific tools, technologies, informational materials, or platforms suggested by participants to support health	• Recommendations for specific tools, apps, materials, or platforms	• Program or mentorship recommendations → Peer/Community Programs	Facilitator: "You also watch videos and reels. Will that be helpful to create awareness?"

Parent Domain	Code Name	Type	Description	Inclusion Criteria	Exclusion Criteria	Example from FGD Data
			management and independent living.	• Suggestions for informational resources or educational materials • Technology or practical resource ideas for health self-management	• System-level recommendations → Clinic/System Improvements • General calls to action → Action & Change Orientation	Participant 4: "Yes, that will be helpful".
Recommendations to Facilitate Transition Process	**Clinic / System Improvements**	**Deductive**	Participant suggestions for how healthcare facilities or systems can better support youth during the transition and independent living, including differences for institutional vs. family-based youth.	• Recommendations for changes in clinic practices, protocols, or environments • Suggestions for how providers, counselors, or health systems should behave differently • Differential recommendations for institutional vs. family-based youth care	• Peer or community program ideas → Peer/Community Programs • Non-clinic tools or resources → Tools & Resources • General change orientation without system specificity → Action & Change Orientation	"so, the facilitators or organizers should also focus on old age people because it all depends upon the social attitudes. It is a social construct, things like stigma or something, this is not by... it is not about our health, it is all about social attitudes like how society is going to see us."
Recommendations to Facilitate Transition Process	**HIV-Specific Health Education**	**Inductive**	Participant recommendations for education specifically about HIV — biology, treatment, disclosure, stigma, and long-term health management — as part of transition preparation; includes recommendations about	• Recommendations for HIV-specific education as part of transition preparation • Suggestions about when HIV education should begin (e.g., from age 12)	• Existing HIV knowledge descriptions → Transition Readiness – Knowledge & Skills • Knowledge gaps without a recommendation	"there is nothing because I said I got everything from my parents and as I said peer counselor was educating me and in my family none of them are educated they don't have literacy on

Parent Domain	Code Name	Type	Description	Inclusion Criteria	Exclusion Criteria	Example from FGD Data
			timing (e.g., beginning education from age 12) and content.	• Advocacy for peer- or provider-delivered HIV education addressing disclosure, stigma, or treatment	→ Barriers to Transition • General health education not specific to HIV → Tools & Resources or Clinic/System Improvements	HIV so, even I didn't have and I didn't even know the abbreviation"
STANDALONE CODE						
Standalone (not nested under a parent domain)	**Photovoice Impressions**	**Inductive**	Participant reflections on the photovoice methodology itself — the experience of taking photographs, sharing images in group discussion, or using photography as a means of expression — distinct from the content or meaning of the photographs.	• Explicit commentary on the photography assignment experience • Reflections on what sharing photographs in the group was like • Statements about the value or limitations of photography as expression	• Descriptions of photograph content or meaning → code under relevant thematic code • Participant interpretations of photos in SHOWeD discussion → thematic codes only • Any life-experience statement prompted by but not about the photography process	"this photo voice session helped all of us to think something very differently and intellectually, not very going common. It helped us to think in a very different manner. Lot of brain work."