



ORIGINAL ARTICLE

Transitioning behaviourally infected HIV-positive young people into adult care: Experiences from the young person's point of view

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Background. There is limited literature on the transition of young people living with HIV/AIDS (YPLHIV) from adolescent/young adult HIV care to adult HIV care in sub-Saharan Africa.

Objective. We aimed to share the experiences of HIV-seropositive young adults transitioning into adult care, to inform best practice for such transitioning.

Methods. We conducted a retrospective evaluation of the transition of 30 young adults aged ≥ 25 years from our adolescent/young adult HIV clinic at the Infectious Diseases Institute, Makerere University, Kampala, Uganda, to adult HIV healthcare services between January 2010 and January 2012.

Results. Six major themes emerged from the evaluation: (i) adjustment to adult healthcare providers, (ii) the adult clinic logistics, (iii) positive attributes of the adult clinic, (iv) transfer to other health centres, (v) perceived sense of stigma, and (vi) patient-proposed recommendations. A model for transitioning YPLHIV to adult care was proposed.

Conclusion. There is a paucity of evidence to inform best practice for transitioning YPLHIV to adult care in resource-limited settings. Ensuring continuity in HIV care and treatment beyond young adult HIV programmes is essential, with provision of enhanced support beyond the transition clinic and youth-friendly approaches by adult-oriented care providers.

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There are a growing number of behaviourally HIV-infected young people who require HIV care and treatment in resource-limited settings. With improved coverage of HIV care, survival among vertically HIV-infected children is increasing. Consequently, an increase in the number of young people living with HIV/AIDS (YPLHIV) who are in need of HIV care and treatment services is inevitable.

YPLHIV, especially adolescents, are usually managed in adult HIV care programmes by providers who are not trained in the provision of adolescent services. This poses a major challenge as providers are often not fully aware of the most common, adolescent-specific challenges of antiretroviral therapy (ART) including adherence, drug-related toxicities (particularly lipodystrophy), HIV status disclosure, late presentation to care, and onset of sexual activity.^[1]

Across Africa, there are few healthcare programmes tailored specifically for behaviourally HIV-infected young people; these YPLHIV are consequently under-served by the healthcare system.^[2,3] Furthermore, with improved survival among

YPLHIV, the need eventually arises to transition them into adult care services. Challenges in relation to such transition include the establishment of trusting relationships, which make paediatricians reluctant to transfer YPLHIV to physicians with adult-oriented healthcare models, and the difficulty most YPLHIV face in disclosing their HIV status to their families and caregivers.^[2] Despite this, there is a scarcity of published information on the challenges faced and successes of transition clinics and models in sub-Saharan Africa.^[3]

In Uganda, there are few adolescent healthcare services available outside of schools,^[4,5] yet there is a national adolescent health policy in place.^[6] Here, to begin to address this gap between policy and practice, we report on the experiences of YPLHIV who have been transitioned from our young adult HIV clinic into adult HIV care.

Methods

The Infectious Diseases Institute (IDI) at the College of Health Sciences, Makerere University, Kampala, Uganda, was

awarded a grant from the Civil Society Fund to provide specialised HIV/AIDS care to HIV-seropositive young adults. The weekly clinic, established and maintained since 2008, is run by a dedicated healthcare team comprised of doctors, nurses, counsellors and peer supporters specialising in adolescent/young adult HIV care. The main emphasis of the clinic is to bridge the gap between paediatric and adult HIV healthcare. This is achieved by offering HIV-seropositive young persons, aged 15 - 24 years, youth-friendly clinical services and psychosocial support.

Between January 2010 and January 2012, of 820 young persons enrolled in the young adult HIV clinic, 80 participants aged ≥ 25 years were transferred to adult healthcare services. Approximately 95% of the young adults acquired HIV through horizontal transmission. The remainder were likely to have been infected perinatally. In February 2012 we performed a retrospective evaluation of the transition of 30 of these young adults, aged 25 - 29 years, from our young adult HIV clinic to our adult HIV clinic.

The IDI young adult transition process

The IDI transition process for young adults from the young adult HIV clinic to full adult HIV healthcare is shown in Fig. 1. For participants, the transition commenced when the young adults reached 25 years of age; however, the timing of transfer was ultimately determined by patient readiness. The clinic counsellor conducted two exit-interview sessions with each young adult. The sessions, which lasted between 15 and 20 minutes on average, were conducted in the privacy of the counsellors' rooms. The first exit session was a one-on-one interaction to acquaint the young person with the subject of transitioning to the adult HIV clinic. During the second exit session, which was also a one-on-one session, an exit questionnaire was completed. The purpose of these sessions was to discuss the transition and to assess patient expectations and readiness (Appendix 1).

Data collection and analysis

One year after transition, a group evaluation was held to assess the participants' attitudes and perceptions of the transition process and to determine how they had adjusted to the adult HIV clinic. An evaluation during a peer-support meeting was selected as the best mode to conduct the research, because it closely

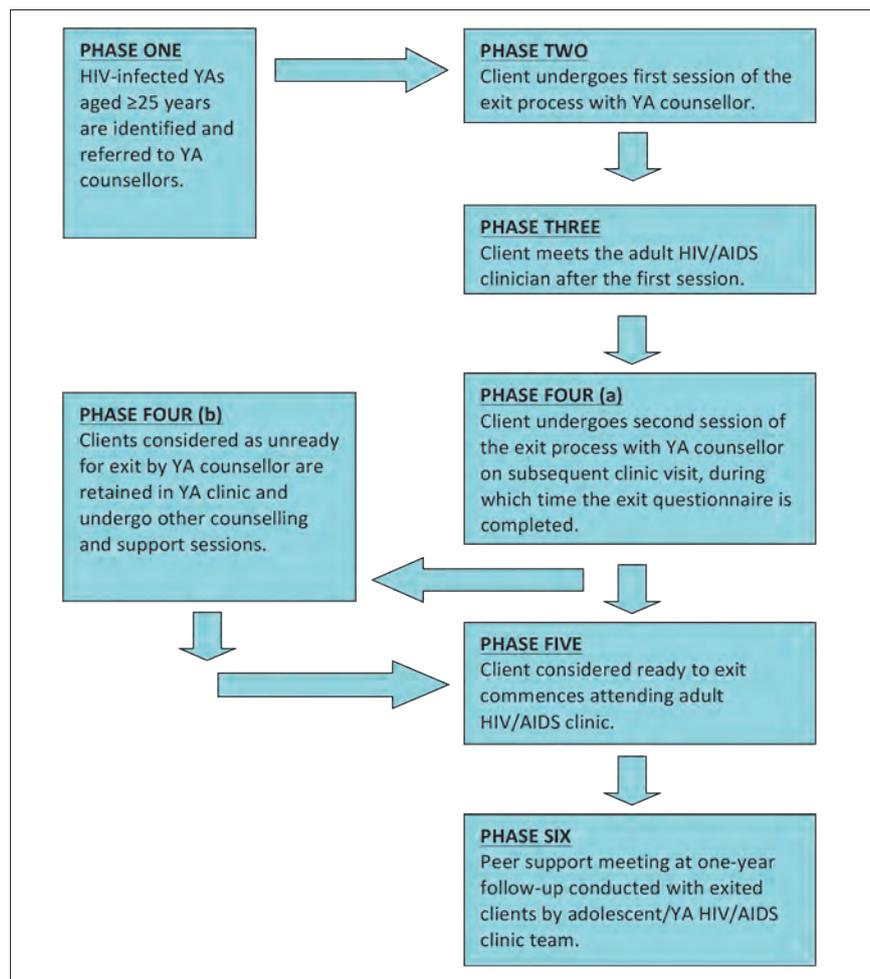


Fig. 1. The Infectious Diseases Institute (IDI) young adult HIV transition model. YA = young adult.

resembled daily social interaction and was less intimidating than a one-on-one interview.

The participants were contacted telephonically prior to the event. The evaluation was conducted at the IDI premises and was facilitated by the co-ordinator and counsellors of the young adult HIV clinic. Participants were reimbursed approximately US\$5 each for transportation costs.

The group evaluation lasted 4 hours and was audiotaped. Discussion was initiated by an open-ended question on the participants' experiences in the adult clinic. All participants provided written informed consent prior to the evaluation, and institutional ethical approval for the evaluation was obtained. Audiotapes were subsequently transcribed verbatim, and qualitative thematic content analysis was conducted by two independent coders: the investigator and a graduate public health student. Qualitative concepts were generated from the data from the evaluation. The two independent coders read the transcripts line-by-line and abstracted key ideas and themes.

Results

Of the 80 participants aged ≥ 25 years who were transitioned to adult HIV care between January 2010 and January 2012, 50 were unavailable for evaluation: 20 had provided incorrect telephone contact details and could not be reached; 15 had other obligations and could not attend the evaluation; 9 resided outside the Kampala district and were therefore unable to attend the evaluation; and 6 had been transferred to other partner clinics. All 30 participants who attended the evaluation had acquired HIV through sexual transmission. Nineteen (63%) of the 30 participants, aged 25 years, partook in the evaluation at approximately one year following the exit questionnaire interview. The remaining 11 (37%), aged 26 - 29 years, partook in the evaluation at 2, 3, 4 and 5 years, respectively, following the exit interview.

Six major themes emerged from the evaluation: (i) adjustment to adult healthcare providers, (ii) the adult clinic logistics, (iii) positive attributes of the adult clinic,

(iv) transfer to other health centres, (v) perceived sense of stigma, and (vi) patient-proposed recommendations.

Adjusting to adult healthcare providers

Most of the participants expressed a sense of difficulty with terminating their relationships with their young adult healthcare providers, because most of them had grown attached to them: 'The first time I came to IDI, I was placed in the young adult clinic and it had become my dad, my mum, my uncle, my auntie, my friend, my family and my life. I was at home in the young adult clinic. You cannot just take my family away from me.' (female, aged 25 years); 'I feel like I am being separated from my mother ... I have been at home in the young adult clinic ... The doctors in the adult clinic now view me like an old man.' (male, aged 26 years)

Some of the participants felt that they were not prepared appropriately for the changes in the adult clinic: 'They need to tell us that the doctors will not treat us like young people anymore. The doctors give us no special attention. If you are not sick, then you are not a problem. They will not even try to find out how your life is.' (female, aged 26 years)

Adult clinic logistics

The young adults described some logistical issues with the adult HIV clinic compared with the young adult HIV clinic. Specifically, they felt that the young adult clinic offered a less busy environment than the adult clinic: 'The waiting hours in the adult clinic are too long and yet in the young adult clinic waiting hours are much shorter.' (female, aged 27 years); 'Some of the health workers in the adult clinic are not youth-friendly and some bark at me. I am always worried about missing lunch.' (female, aged 25 years)

There were also logistical issues raised due to the large clinic size: 'At one of my clinic appointments, I was told that my file had gotten lost and was told to sit and wait. I sat at the waiting benches for almost the whole day and yet I had come at 8 a.m. in the morning and left at 3 p.m. in the afternoon. This had never happened to me in the young adult clinic.' (female, aged 28 years); 'Files begin to get lost when you are moved to the adult clinic and not when you are in the young adult clinic.' (male, aged 26 years)

Positive attributes of the adult clinic

Although most of the young adults acknowledged difficulties in coping with the transition, some appreciated the adult clinic services, the specialised healthcare and the tools that were used to decongest the adult clinic: 'Ever since I was transited into the adult clinic I have gotten special care ... maybe it is because at the time of transition, I was pregnant. I was given a special doctor to attend to my needs. My baby and I are healthy and well. I am happy with the services.' (female, aged 27 years); 'I have not faced any difficulties since I started attending the adult clinic. When I come to the clinic, I cancel all the day's programmes and devote the day to the clinic. I do not mind about the amount of time I spend at the clinic provided I have been seen by the doctor and gone home with my medications.' (female, aged 26 years); 'I have not had any problems in the adult clinic. As soon as I was transferred to the adult clinic, I was given a green card, which basically means that I see the health worker every 3 months. Every other month I get my drugs from a prescription window.' (male, aged 26 years)

Transfer to other health centres

Some of the young adults who had been transitioned from the young adult clinic expressed discontent when they had been transferred to other health centres: 'I was not happy when I was transitioned to the adult clinic. As soon as I was transitioned I was told that I had to be transferred to another health centre outside IDI. When I reported to that health centre, I was told that the centre only works on two days in a week and yet I have a job.' (female, aged 26 years)

Perceived sense of stigma

Some participants associated the adult clinic with stigma: 'I do not like the way the adult patients look at me in the adult clinic. They look at me in an accusing way ... like I am someone who sleeps around.' (female, aged 26 years)

Some participants conveyed a fear that the adults may be a frightening group: 'It is very difficult for me to walk in the adult clinic ... sit with adults and wait for my turn to see the doctor without being asked what I am doing in the clinic. I am a short, thin girl and usually get mistaken for being a teenager ... when I sit in the adult clinic, I feel totally lost.' (female, aged 25 years)

Patient-proposed recommendations

Some participants felt that the adult HIV clinic healthcare providers needed to acquire skills specific to the treatment and management of YPLHIV: 'Some of the doctors in the adult clinic should work in the young adult clinic so that they can learn how to handle young people. Some of them treat us like adults and yet we are not ... we need more time.' (female, aged 25 years)

One of the participants still felt the need for additional support extending beyond the adolescent and young adult HIV/AIDS care programme: 'I was among the first young adults to be exited from the young adult clinic. It would be good if you got us a special day – like Thursday or Friday – for the exited young adults, so that we can continue to meet others.' (female, aged 29 years)

Discussion

The transition process for YPLHIV to routine adult HIV care is a complex, clinical and psychosocial process that varies from patient to patient. Given the paucity of available data specific to this in resource-limited settings, we accordingly aimed to provide insight into and propose a model for such transitioning.

As much as transition into adult care is possible for YPLHIV, our evaluation showed that stigma still persists among these young people. The qualitative results of our study corresponded with similar findings by others when transitioning adolescents with other chronic diseases into adult healthcare in developed countries.^[4-8] In our study, adjusting to the concept of adult care, an adult-oriented clinic environment and a perceived sense of stigma were some of the challenges faced by young people transitioning into the adult services. These findings were similar to those of others when transitioning adolescents with perinatally acquired HIV infection into adult care.^[4-12] In contrast, a few participants acknowledged the benefits of the adult-oriented HIV clinic, reiterating that the process may vary for each patient.

Although the transition process itself did not involve caregivers, the importance of the social support system was emphasised during the exit process. The rationale for not involving caregivers in the transition process is to enhance patient autonomy. However, it is

possible that involvement of the caregivers would have provided more insight into some of the challenges faced by the young adults during and after transfer to adult care.

In the literature, there are a number of models that have been developed for transitioning adolescents and young adults with chronic health conditions into adult care. These models, however, have been developed in resource-rich, developed countries. The Maestro Project systems navigator model for diabetes mellitus and the Young Adults with Rheumatic Diseases (YARD) clinic transition model are two examples of disease-specific transition care programmes that were designed to provide support for youths with chronic diseases.^[14] Other transition models that are not disease-specific were designed to link young adults with chronic conditions in general to adult care.^[14,15] All of these models emphasise the importance of a social support system, including parents and families, in the transition care process. Each model also differs, as the principles that govern transition across these models differ. For example, the Maestro systems navigator model is governed by five principles: enhancement of patient autonomy, ensuring collaboration between healthcare providers, equipping with negotiation skills, providing community resources, and having a designated professional who takes responsibility for transition.^[14] Other programmes emphasise the provision of developmentally appropriate care, shifting the responsibility to the adolescent, and the provision of a portable summary of the patient's healthcare needs and a clear transition plan in the patient's file.^[14]

With regard to adolescent HIV care, the 'movin' out' model was developed by a special adolescent clinical team in the United States.^[16] The model is essentially a transitioning protocol of 5 phases and is fluid, allowing a young person to revert to a prior phase or to become stagnant at a particular phase. The protocol necessitates that a multi-disciplinary transition team, comprising nurses, social workers, peer educators, psychologists and physicians, take charge of the process of transition.^[16]

Against this backdrop, we formulated a transition model that would provide guidance for transitioning YPLHIV from young adult HIV programmes into adult HIV care in developing countries, on the basis of enhancing patient autonomy. Despite the limitations, the key findings of the evaluation were that moving to the adult clinic is difficult for YPLHIV. As an implication, there is the

need for continual follow-up and for some of the adult care providers to be part of the adolescent/young adult team.

Study limitations

The study had several limitations. All 30 participants who partook in the evaluation had acquired HIV through sexual transmission. It is possible that there could have been major differences between sexually infected young people and perinatally infected young people. The results may, therefore, not be generalisable to vertically infected young people transitioning into adult HIV care. Secondly, there was a low response rate to participation in the evaluation (30/80; 38%); hence, the sample size was small. Adding to this, the study was based on a single-centre evaluation (one facility). As much as we sought to illuminate the area of transitioning young HIV-positive people into adult HIV care in the study, the data obtained in our evaluation may not be generalisable to other young adult HIV cohorts.

Conclusion

Ensuring that YPLHIV continue to access care beyond young adult HIV programmes is essential in assuring continuity in HIV care and treatment across Africa. The directions emerging from this study are clear: the provision of enhanced support beyond the transition clinic and youth-friendly approaches by adult-oriented care-providers to young people are both key to continuity of care.

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