



Transitioning Adolescents with Perinatally Acquired HIV from Paediatric to Adult Centered Care: Caregivers' Perspective

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Author's contribution

This work was carried out in collaboration among all authors. All authors read and approved the final manuscript.

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ABSTRACT

Aim: To investigate caregivers' attitude towards transitioning HIV-positive adolescents from paediatric to adult centered care as well as understanding their perspective of transition inhibitors and facilitators.

Study Design: We used a descriptive qualitative design and purposively selected principal caregivers of adolescents aged 15 to 19 years with perinatally acquired HIV who had been attending the paediatric infectious diseases clinic for at least 12 months before the study.

Place and Duration of Study: Rivers State University Teaching Hospital, Port Harcourt, Nigeria. The study was conducted from August 2020 to November 2020.

Methodology: We included principal caregivers whose wards were not cognitively impaired, whose HIV serostatus had been disclosed to them and who had been attending the Rivers State University Teaching Hospital paediatric infectious diseases clinic for at least 12 months before the onset of the study. Fifteen In-depth interviews were conducted and data was analyzed using the

thematic analysis method with Atlas ti data qualitative software version 7.5.21. The sample size was determined when data saturation was reached.

Results: Most principal caregivers did not understand their role and were not involved in preparing their wards for the transition to adult care. Perceived inhibitors to transition were anxiety on severing the long-term relationship with the paediatric health care team and concern that adult physicians may not be as caring as those in the paediatric clinic. Seropositive caregivers suggested that taking their wards along with them to their appointment at the adult clinic would facilitate transition.

Conclusion: Principal caregivers were unaware of their roles in the transition process, healthcare providers should actively involve and educate them to ensure a smooth transitioning to the adult centered care.

Keywords: Adolescents; caregivers; perinatally acquired HIV/AIDS; health care transition.

1. INTRODUCTION

Transition from paediatric Human immunodeficiency virus (HIV) care to adult services is a critical step for maintaining good outcomes among adolescents and young adults[1–3]. High rates of treatment non adherence, emergence of drug resistance and loss to follow up have been registered among transitioned adolescents [4–8]. These findings have been attributed in part to poorly conducted transition processes[1,9,10]. With an estimated 97,000 adolescents living with HIV (ALHIV), Nigeria bears the highest burden of adolescent HIV in the West and Central African regions[11]. Nigeria has no national guidelines for transition of adolescents in HIV care, and transition practices vary between healthcare facilities[12]. An evaluation of current transition processes is required to enable the development of an acceptable model of healthcare transitioning for adolescents in Nigeria [10,12].

The World Health Organization (WHO) defines HIV care transition as a planned movement from paediatric models of care to adult services, the goal of which is to support adolescents gain life skills to independently manage their care [13]. A comprehensive transition plan addresses the distinct and diverse needs of adolescents living with HIV and should involve the active input of adolescents, their families and the healthcare team[14–16]. “Parent involvement” is one of the key of features of translational care that has been strongly associated with good outcomes in children with chronic medical conditions[15,17]. Parental support for autonomy has also been associated with greater consistency in children’s adjustment across social and academic domains[18]. Efforts to improve HIV self-management need to involve not only the adolescent but also their caregivers/families [19].

The healthcare provider should however be aware that certain parental behaviors such as the difficulty in releasing and transferring responsibility discourages autonomy in their wards[20] and take steps to discourage them.

The transitional period in HIV care is deliberately focused to facilitate the successful transfer of HIV-management responsibility, from caregiver to adolescent [21]. Viner [17] identified the ability to take responsibility for their medications and be seen by themselves in clinic visits as necessary skills that need to be developed during this period to enable an adolescent function effectively in the adult clinic. Family care givers play a vital role in facilitating the development of these skills by actively allowing the adolescent to gradually take on the responsibility to independently manage their own care[22].

Several studies in low and middle income countries (LMIC) have investigated the transition to adult care of adolescents with chronic medical conditions such as sickle cell disease and asthma[23–25]. A few studies involving ALHIV have focused on transition readiness assessment[26], patient and healthcare providers’ perspectives on transition and some have investigated transition programs[12,27]. Very little is known about caregiver perspective on transitioning ALHIV from paediatric HIV care to adult services especially in Nigeria.

Some investigators [15,19,28] acknowledge that parental involvement will likely impact the adolescent’s transition to self-care. Health care providers may not recognize the contributory role of parents in self- management promotion[29] hence there is a need to investigate current practice to provide data to inform healthcare providers in the development of more collaborative transition programs that encourage

parental involvement in facilitating autonomy and nurturing confidence in the ALHIV to empower them to make decisions about their care [17].

In this study, we explored principal caregiver perspective of their role as regards the preparation of their adolescent wards for transition into adult care. We evaluated their facilitation of the development of self-management skills in the ALHIV by their attitude towards promotion of medication autonomy and self- advocacy in clinic appointments. We also elicited their perceived inhibitors and facilitators of the transition process.

The aim of this study is to ascertain family caregiver's understanding of their role in the transition process, their attitude to the transition process and their suggestions of specific ways in which they can become more actively involved in the process. We also identified their perceived inhibitors and facilitators of the transition process, to guide healthcare providers in the development of more successful transition programmes

2. METHODOLOGY

2.1 Study Design

This is a cross-sectional study that employed qualitative method of data collection.

2.2 Study Site

The study was conducted in Rivers State University Teaching Hospital (RSUTH) a tertiary referral hospital located in Rivers state, Nigeria. In this hospital, children are seen in the paediatric outpatient clinic which is separate from the outpatient clinic for adults although both clinics are in the same hospital complex.

2.3 Study Population

The study participants consisted of the principal caregivers of adolescents aged 15 to 19 years with perinatally acquired HIV.

2.4 Inclusion Criteria

The eligibility criteria for the study were as follows: Principal caregivers whose wards were not cognitively impaired, whose HIV serostatus had been disclosed to them and who had been attending the Rivers State University Teaching

Hospital paediatric infectious diseases clinic for at least 12 months before the onset of the study.

2.5 Exclusion Criteria

Caregivers who refused to consent to the study and who were ill at the time of data collection were excluded from the study.

2.5.1 Sample size determination

Principal caregivers who visited the paediatric HIV clinic with their adolescents were purposively selected. Data was collected until a point when adding more participants to the study, does not result in additional perspectives or information and data collection ended when data saturation was reached[30] . Adequate sample size to attain this point of saturation has been suggested to fall within 5-50 participants[31]. Fifteen principal caregivers participated in the study.

2.5.2 Data collection instrument

Socio demographic data was collected before the study began. An In-depth interview guide was used to elicit information from the principal caregivers on the transition knowledge and role, support of ALHIV towards self -management and their perceived inhibitors and facilitators of transitioning from paediatric HIV care to adult services.

2.5.3 Data collection procedure

Principal caregivers who visited the paediatric HIV clinic with their adolescents were purposively selected. A nurse in the paediatric HIV clinic who we had explained the study to, talked to parents who met the eligibility criteria when they came to the clinic with their child and then referred them to us the researchers. The purpose of the study was explained to the participants and consent was sought from them before recruiting them into the study. Privacy was assured and participation was voluntary. The interviews were conducted in English/ Pidgin English, probes were used, and each interview lasted for about 20-30 minutes. The interviews were audio recorded with permission from participants and notes were taken. The study was conducted from August 2020 to November 2020. The study instrument was pretested by conducting first interviews to ensure the questions were well understood and revisions were made.

2.6 Data Analysis

Data was analyzed using thematic analysis method with ATLAS.ti scientific software version 7.5.21 [32]. Thematic analysis is an appropriate method of analysis for seeking to understand experiences, thoughts, or behaviours across a data set [33]. The interviews were transcribed, and the field notes used where necessary. Typed transcripts were read severally and cleaned, the transcripts were coded, and a code book was developed both inductively and deductively with themes, sub-themes and codes[33]. A total of 22 codes were derived from the fifteen transcripts. Coding is the process of labeling and organizing your qualitative data to identify different themes and the relationships between them [34]. Here we assigned labels to phrases that represented important and repetitive themes in each response. Using thematic analysis we extracted themes from text, analyzed the words and sentence structure.

3. RESULTS

3.1 Socio-Demographic Characteristics of Caregivers

The caregivers comprised of nine females and six males ranging in age from 29 to 67 years old with a median age of 55 years old. Three had completed tertiary education, eleven had completed secondary school, and one had completed primary education. Ten were married, two were divorced, two were widowed, and one was single. The majority of the caregivers were Christians. Their relationships with the adolescents were mostly parent-child relationship, with some grandchildren, nieces, and nephews.

3.2 Caregiver awareness of adolescent transition from the paediatric HIV clinic and their role in the transition process

The caregivers were asked if they were aware their wards would be transferred to the adult clinic at age 18 years and their involvement in the transition process.

The majority of the caregivers were aware that their children will be transferred to the adult clinic when they reached the age of eighteen. The caregivers expressed diverse emotions about their ward's relocation to the adult clinic; some were glad, some sad, and others were apathetic. Most of the caregivers had not discussed transition with their ward. Despite the lack of a

transition plan, most caregivers were already implicitly facilitating the change in their wards to build self-management skills and other developmental expectations. It's worth noting that a couple of caretakers were hopeful that the condition would be cured before their wards were old enough to transition.

I think It's okay to transfer to the adult clinic, it will help her to understand more about this infection and I believe by then she must have understood and be ready for more advanced drugs that will be administered to her to enhance her life _Female_29 years

It is not easy taking these drugs daily, but I keep encouraging him. I pray that before he transfers to the adult clinic the thing would have cleared up Female_43years

3.3 Caregivers attitude towards promoting HIV self -management skills among their wards

The caregivers were asked if they would give medication responsibilities to their wards and allow their wards practice self-advocacy skills by letting them see the pediatrician alone.

Some caregivers were hesitant to give their adolescents medication responsibility because they were concerned that they would not take their medications as prescribed and become ill. In addition, few of the caregivers said it was difficult to get their wards to take their medications, while others said they were tired of giving the drugs to their wards on a daily basis. Most parents were reluctant to let their children see the pediatrician on their own. Some parents prefer to be present during the clinic visit but allow their wards to speak with the paediatrician, while others speak with the paediatrician during clinic visits, allowing their children to speak only when asked. A few parents intend to keep speaking with the paediatrician during clinic visits until their wards are old enough to see a physician at the adult clinic.

He is stubborn so it is a bit difficult talking to him about his medical condition. I prefer to give him his medications myself to make sure he takes it, if I tell him to take it, he may not take it, he does not listen Male_42 years

I don't have a problem with my son talking with the doctor but I have to stay with him, it's just that I don't want him to tell others about the sickness Female_34 years

She is taking her medications herself but sometimes I check to make sure she is taking it.....I don't want her to see the doctor on her own, she is not mature enough for that, she may not know what to askshe may not understand what the doctor says Male_45 years

they were hesitant to end their long-standing relationship.

This is my late daughter's child... When I brought him to the paediatric clinic he was 2 years and I had just lost my daughter. I was scared I would also lose him but they encouraged me and have been taking care of him. Now he is 16 years old if he has to go to the adult clinic I will really miss the doctors in the paediatric clinic. Female_60years

They attend to us very quickly since they know we are coming from a far place. The nurses and doctors are nice most of the time; I hope the doctors and nurses in the adult clinic are also good. Female_29 years

The staff are very friendly and they also give us drugs and check our CD4 count... they also encourage us. Female_34 years

Table 1. Socio-demographic characteristics of caregivers

Characteristics	N=15	%
Sex		
Female	9	60.0
Male	6	40.0
Age		
25 - 35	2	13.3
36 - 45	4	26.7
46 - 55	6	40.0
56 - 65	2	13.3
66 - 75	1	6.7
Marital status		
Never married	1	6.7
Married	10	66.7
Divorced	2	13.3
Widowed	2	13.3
Religion		
Christianity	13	86.7
Islam	1	6.7
Traditional	1	6.7

3.4.2 Fear of Stigma

Some caregivers were concerned that their wards would be stigmatized at the adult clinic; fear of being recognized was cited as a major barrier. Some people also believed that there would be service changes and that the adult clinic would be busier. Caregivers who had HIV and were already attending the adult clinic, on the other hand, expressed no concerns about stigma.

I feel she might be stigmatized, she will meet more people and they will know she has the virus. Female_29 years

3.4.3 Concern of the health service delivery in the adult clinic

Some caregivers were concerned about the quality of health care their wards would receive when they transferred to adult centered care. Some barriers perceived include; negative attitude of health workers, delay in service provided and quality of care rendered. Others reported limitations included caregivers' financial constraints and time constraints.

The services might not be same, attitude of health workers there might not be same, and it might be stressful because the delay in attendance will be longer. Female_6 0years

I hope they will be patient and not shout at my brother in the adult clinic, you know he is still young. Female_29 years

3.4 Caregiver Perceived Inhibitors to Transitioning

The caregivers were asked of any perceived inhibitors to smooth transitioning of their wards to the adult clinic at age 18 years. From the responses, the caregivers perceived some barriers that might hinder the smooth transitioning of their wards to the adult clinic and they were grouped into three subcategories; fear of leaving the paediatric clinic and letting go long-standing relationship between the paediatric providers and families, fear of stigma and the concern of the healthcare service delivery in the adult clinic.

3.4.1 Fear of leaving the paediatric clinic and letting go long-standing relationship between the paediatric providers and families

The majority of caregivers reported they appreciated the services provided at the pediatric clinic particularly the kind services and encouragement. They were pleased with the level of care and management they received and

I will need more finances ...transport fare because right now, I have no job and no help is coming from anywhere so transport fare taking him to the adult clinic will act as a barrier and also his school, since he's still in secondary school, he might also not be going everyday so that he won't drop out from school. Male_42 years.

By assisting us with transport fare so that we can be meeting up every time so that he won't end up skipping his drugs Male_42 years

By ensuring that services they will get is friendly and easier like it is here Male_54 years

3.5 Caregiver's perceived facilitators of their wards transition to adult clinic

The caregivers were asked of any perceived facilitators that would facilitate a smooth transitioning of their wards to the adult centered care. The caregivers enumerated a few factors that may serve as facilitators to smooth transitioning to adult centered care. Some of the caregivers suggested that educating their wards and supporting them emotionally, socially and physically would be beneficial. Others argued that allowing them access care at the paediatric clinic once in a while might facilitate their transitioning

I know what I need to do is to educate her more about this infection, to help her know the importance of taking her drugs daily, and also encouraging her, telling her it's not the end of the world if she takes her drugs regularly and being consistent in taking her drugs she will be fine and can do anything Female_29 years.

By allowing him to come to the paediatric clinic independently, meet with the doctor and collect his drugs from the pharmacy. Letting him know that life is not that rosy and instilling in him the habit of adhering to his drugs Female_60years

Furthermore, some of the caregivers proposed introducing them to the adult clinic before their transfer date, as well as offering better and friendlier services at the adult clinic by the healthcare providers. Others argued that providing financial aid might make the move to the adult clinic go more smoothly.

Well, nothing she will go when its time. Maybe if I take her with me to for my appointment at the adult clinic before it is time for the transfer Female_34 years

Liaising with the health workers in the adult clinic so that they can change their attitude and ensure people don't waste all their day over there Female_60 years

4. DISCUSSION

The findings in this study reveal that several factors influence caregiver perspective towards the transition of ALHIV from Paediatric to adult centered care including the awareness of their role in transition, their readiness to transfer HIV care to their wards and the motivation to support transition. Their perception of facilitators and inhibitors of transition was related to their concern for breaking ties with the paediatric healthcare team and adult HIV healthcare service delivery.

4.1 Awareness of Role in Transition

Most caregivers were aware that their wards will be transitioned to adult care and they agree that the ALHIV should have significant HIV self-management skills by the time of transition, however most caregivers were not aware they have a role to play in the ALHIV's transition to self- management and very few had discussed the transition process with the ALHIV or the paediatrician. A similar finding has been reported among caregivers of ALHIV [35,36] and those of patients in pediatric diabetes care[37]. Our findings reveal that family caregivers in this study are not adequately prepared for transition. The paediatric healthcare team needs to stress the importance of supporting the ALHIV to self - care overtime and collaborate with them to come up with a transition plan[18,38]

4.2 Readiness to Transfer HIV care to ALHIV

Most caregivers in this study believe that the preparation for transition to adult care should begin at the time of HIV status disclosure, by which time according to them the ALHIV is developmentally mature enough to begin these discussions. Suggested age of disclosure among the caregivers ranged between 15 – 18 years similar to that reported by Eneh [39] in a study on mother's perception of disclosure conducted in the same region. Several studies agree that the transition process should be initiated according

to the level of maturity of the ALHIV[1,40], however, Viner[17], recommends beginning these discussions in early adolescence, from 13 to 15 years of age. Healthcare providers should educate families about the value of early disclosure to facilitate the initiation of the discussion and planning for transition to adult care.

Families play an important role in the medication taking behaviours of youth[19,41]. According to participants in a study conducted by Reiss[22], parents should start giving responsibility of medical self-care to the adolescent during the second stage of transition labelled "Age of responsibility". When asked if they give medication responsibilities to their wards most of the care givers in this study were not eager to relinquish responsibility of medication adherence to their wards because of fear of poor adherence and bad outcomes. This is similar to what has been reported in previous research on health care transition [19]. Care giver reluctance to transfer responsibility limits the development of self-management skills and the adoption of tools to help ALHIV regularly take their antiretroviral medication.

When asked if they allow their wards practice self-advocacy skills by letting them see the pediatrician alone, some caregivers would not allow this and a few plan to continue to see the pediatrician along with their ALHIV until the time they begin seeing an adult physician. This attitude has also been previously reported by Raymond et al[37] and the situation is likely to contribute to decreased follow-up and less than optimal medical outcomes after transition to adult care. The ALHIV who has not had the time to develop confidence and practice autonomy will struggle to adapt to adult centered care where the expected practice is lone consultation. The shift from predominantly two-way communication between the parent and clinician about a child's health care to three-way communication between the adolescent, parent, and clinician is reported to foster smooth transition to adult care[41]. The Got Transition Center's elements for the assessment of healthcare transitioning activity[16] recommend that from the age of 12-14 years patients should be consistently seen alone during preventive clinic visits without the caregiver/ parent being present. Paediatricians can foster autonomy by advocating for time alone with patients during clinic visits [20].

It is reported that transition can also be a challenging time for the family caregiver as they

give up control and the right to decision making as the adolescent becomes more autonomous[22]. Studies on family involvement reveal that caregivers may require support to develop autonomy promoting skills and to employ family-based interventions to prepare the ALHIV for HIV self-management[20].

4.3 Motivation to Support Transition

In the course of this study the family caregivers became more aware of their role in supporting

ALHIV and were motivated to support the transition, hence when the caregivers were asked of any perceived facilitators that would facilitate a smooth transitioning of their wards to the adult centered care, they suggested offering praise, encouragement and providing alarm clocks and phones to facilitate medication adherence. These caregiver supporting behaviors reinforce health-related autonomy and increase competence, by facilitating a "feedback loop" in which parental praise results in increasing competence in self-management tasks, this in turn increases parent's trust and engenders transfer of more responsibility[20]. Lanyon[21] reported similar caregiver supporting behaviors and is in agreement with Heath [42] that caregivers can be key facilitators of the healthcare transition process when given clarification on their role and support from healthcare providers. In this study a few of the caregivers receiving antiretroviral therapy (ART) care in the adult clinic offered to take the ALHIV along with them to the clinic to reduce their apprehension of the adult clinic and facilitate the smooth transition to adult centered care.

4.4 Reluctance to Break Ties

The reluctance to break ties with the paediatric team with which they had formed a bond over the years was perceived by majority of caregivers in this study as an inhibition to smooth transition to adult care. This is similar to reports in several studies[40,43,44].

4.5 Concern for adult Healthcare Service Delivery

Other inhibitors to transition including the concern by caregivers that the physicians in the adult clinic may be impatient or demand a higher degree of autonomy from the ALHIV, also aligns with the findings in other studies [44]. The

concern as regards the service delivery in adult clinics may not be unfounded as research conducted among physicians in adult HIV healthcare indicated a self-assessed need for further training on how to handle adolescents [45]. Overcrowded adult clinics as a perceived inhibitor to transition is also commonly reported in studies on transition in other low and middle income countries (LMIC) [9,46,47]. Unlike previously reported [44] stigma was not a major issue of concern as an inhibitor to transitioning care in our study.

5. IMPLICATIONS FOR FUTURE RESEARCH

There is a need for further research to evaluate the effect of family caregiver involvement in the promotion of HIV self - management on post transition clinical outcomes in ALHIV.

6. CONCLUSION

This study highlights the need for family caregivers of ALHIV to have a better understanding of transition and their role in the transition process. Healthcare providers should make more effort to involve caregivers in the transition process and support their skills in facilitating autonomy. Care givers can assist in the transition services by introducing adolescents to the adult clinic in facilities with limited staff. They can also collaborate with the healthcare team in the development of the transition program and their constructive feedback is important in the evaluation and development of strategies to improve the transition process.

CONSENT

All authors declare that written informed consent was obtained from the participants in this study.

ETHICAL APPROVAL

Ethical approval was obtained from RUSTH Research Ethics Committee. Permission was also sought from the Chief Nursing Officer in charge of the clinic. Study approval number: RSUTH/REC/2020019

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COMPETING INTERESTS

Authors have declared that no competing interests exist.

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