Experiences of transition to adult care and readiness to self-manage care in young people with perinatal HIV in England

Running head: Transition to adult care in young people with HIV

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ABSTRACT (149/150 words)

Background: There are few data on young people's own experiences of transferring from paediatric to adult care, or readiness to self-manage care.

Methods: 132 young people living with perinatal HIV aged 14-25 years answered questions about transition experiences.

Results: 45 (34%) were in paediatric care (median age 16 [IQR 16,17] years), of whom 89% reported that transition discussions had begun, at median age 15 [14,16] years. Young people in adult care were more likely than those in paediatric care to self-manage appointments (90% vs 42% respectively, $p<0.001$), and know their ART drugs (55% vs 37%, $p=0.033$). Knowledge of most recent CD4/viral load was slightly better for those in adult care (48% vs 31%, $p=0.059$); naming side effects of ART was similar (71% vs 60%, $p=0.119$).

Conclusions: Transition discussions occurred before movement from paediatric to adult care. Further education around ART, potential side effects, and CD4/viral load knowledge is required.

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BACKGROUND

Transition to adult care is defined as the purposeful and planned process of supporting young people to move from children's to adults' services.[1] A lack of appropriate support may lead to disengagement from care and a lack of continuity of care, and thus successful transition is an essential step for the achievement of optimal health in adulthood. Underlying the process of successful transition is the young person taking greater personal autonomy, including taking responsibility for their own health, making their own clinic appointments, and taking responsibility for medication adherence.

Transition from paediatric to adult care is relevant to young people with a variety of chronic conditions, such as diabetes and also HIV. Transition is a relatively recent concept in the field of paediatric HIV; with increased access to antiretroviral therapy (ART) globally, large numbers of young people with perinatal HIV (PHIV) already have transferred to adult care and will continue to over the coming decades.[2] However issues around young people's abilities to receive and process information together with a lack of communication have been cited as being the greatest barriers to successful transition from HIV paediatric to adult care.[3] Self-efficacy in healthcare navigation is essential to maximise retention and adherence to ART. Several factors may hamper access to care for young people with PHIV in the UK, including having English as a second language and lower socio-economic status.[4]

It is generally considered that there is no superior transition model and that the key to successful transition is an approach which is flexibly paced to the individual needs of the young person.[5] Some will transition from a family clinic to an adult service, while others will transition from a paediatric clinic to a young person's clinic. We describe experiences of the transition process among young people with perinatal HIV in the Adolescents and Adults Living with Perinatal HIV (AALPHI) cohort in England.

METHODS

The AALPHI cohort study evaluated the impact of HIV on young people with PHIV and HIV negative young people, many of whom were siblings of the HIV positive group or had a mother living with HIV. Detailed methods have been reported elsewhere.[4] Briefly, PHIV young people were aged 13 to 21 years, had a history of paediatric care in the UK/Ireland, and were aware of their HIV status for >6 months at enrolment. During follow-up interviews in 2016/17, 132 young people completed an evaluation on transition experiences on a paper questionnaire. Questions were introduced half way through follow-up interviews and so not all young people who had follow-up interviews for the study had transition experience data. Transition questions were adapted from the USA Paediatric HIV/AIDS Cohort Study [6], enabling comparisons of the UK and USA cohorts.

PHIV young people in paediatric care were asked whether their clinic had talked to them about the process of transitioning and how old they were when these discussions first took place. PHIV young people in adult care were asked about the type of transition (e.g. direct transfer vs. period of shared visits between paediatric and adult providers), how prepared they felt at the time of transition, who had chosen the adolescent/adult clinic (themselves, family or doctor), and how they rated adult care compared to paediatric care.

All participants were asked questions about their readiness to self-manage their HIV care and satisfaction with current care, including whether they could manage their own appointments, name their HIV medication and possible side effects, and tell someone their latest CD4 and viral load. Participants were also asked about their ART adherence via computer-assisted survey interviewing, and the association between knowing how many pills were taken each day or being able to name one's HIV medication and adherence was explored. The two adherence measures used were missing any doses in the last 3 days ("three day non-adherence"), and also having missed >2 days of doses in a row in the last month ("last month non-adherence").

Data were analysed using STATA version 15 (Stata Corp, College Station, Texas, USA). Descriptive statistics summarised data, and Chi squared and Fisher's exact tests compared proportions. Results are presented for non-missing values; missing values were for <10% of study participants unless specified. Due to small numbers in some categories for some questions, answers were analysed comparing "yes, I do this" to "no, I need to learn how to do this" combined with "no, someone else needs to do this for me".

RESULTS

Participant characteristics

Of the 132 PHIV young people included, 45 (34%) were seen in paediatric care, of whom 37 (82%) were in paediatric clinics and 8 (18%) in adolescent clinics within paediatrics. Two-thirds (87/132, 66%) of young people were seen in adult care, of whom 74 (85%) were in an adolescent clinic and 13 (15%) in an adult clinic. Twenty (44%) of those in paediatric care and 28 (32%) of those in adult care were male, and the median age of paediatric care attenders was 16 [interquartile range (IQR) 16, 17] and adult care 20 [19, 22] years respectively. The majority of participants (85% overall; 78% in paediatric care and 89% in adult care) were of black ethnicity, and around half (56% vs. 47% respectively) were born outside the UK or Ireland (Table 1). The majority (89%) of those in paediatric care were in full time education, compared to 59% of those in adult care. Almost all of the participants (95%) across both care settings had been seen in clinic in the previous 6 months.

Process of transition

Of the 45 young people in paediatric care, 33/37 (89%) reported that discussions about the process of transition from paediatric to adult care had already begun, and had started at a median age of 15 [14, 16] years. Of the 87 young people in adult care, 64 (76%) reported direct transfer from a paediatric to adult clinic, at median age 17 [16, 18] years, and 20 (24%) reported a process of shared care transfer, at median age 16 [15, 17] years, with a median of three [2, 4] shared paediatric/adult appointments. Nineteen (23%) young persons moved hospital when transitioning to adult care.

Preparedness, choice and rating of care

Of those in adult care, approximately one in five (19/84, 23%) said they felt “very prepared” and just under half (41/84, 49%) said they felt “quite”’ prepared at the point of transfer to adult care, and 20% (19/83) reported that family members had helped to choose the adult clinic. Figure 1 shows participant’s rating of adult care compared to paediatric care. Most rated adult care as better or no different to paediatric care for services and support offered. Only 14% (12/85) rated the adult clinic environment as worse than paediatrics; 9% (8/85) rated times of clinic, the amount of responsibility you have, the amount of support you are given, and how well the services are tailored to meet your needs worse following transition to adult care. Similarly only 8% (7/85) and 7% (6/85) rated flexibility of appointment times and the staff worse than paediatrics respectively.

Self-management of care and adherence

Those in adult care were more able to self-manage their care than those in paediatrics (Figure 2). Higher proportions of adult care attenders reported that they were able to self-manage their appointments (78/87 (90%) vs. 19/45 (42%) respectively, p<0.001), make their own travel arrangements to clinic (84/87 (97%) vs. 28/45 (62%), p<0.001), inform the clinic when an ART prescription was needed (85/87 (98%) vs. 25/43 (58%), p<0.001), and name their ART drugs (48/87 (55%) vs. 16/43 (37%), p=0.033). Knowledge of one's most recent CD4 and viral load values was slightly better for those in adult care (42/87 (48%) vs. 14/45 (31%), p=0.059), however being able to name possible side effects of one's ART was similar in both groups (62/87 (71%) vs. 26/43 (60%), p=0.119). High proportions in both groups knew how many pills they took each day (86/87 (99%) adult care vs. 39/43 (91%) paediatric care, p=0.003) and could tell their doctor how their health had been (95% (83/87) vs. 93% (42/45) respectively, p=0.615).

Of 118 young people with transition and adherence data, 20/61 (33%) of those who were not able to name their HIV medication reported three day non-adherence, compared to 17/57 (30%) of those who could name their medication (p=0.729), and similarly 27/61 (44%) vs. 20/57 (35%) respectively for last month adherence (p=0.309). Knowing the number of pills taken each day was also not associated with three day or last month non-adherence (data not shown).

Satisfaction with current care

Of those in paediatric care, 41 (91%) were happy/very happy with their clinic and 42 (93%) happy/very happy with the staff; the equivalent numbers in adult care were 81 (93%) and 81 (93%) respectively.

DISCUSSION

Our findings suggest that many young people with HIV had a well-managed process of transition to adult care. For those still in paediatric care, most reported that transition discussions had started, following good practice guidelines.[1, 5, 7] Approximately three quarters of the young people in adult care reported direct transfer from paediatric to adult clinics and around a quarter reported shared care transfer. The proportion reporting direct transfer was higher than expected given recommendations for a period of shared care across transition.[1, 7]

Most young people in adult care said they felt prepared at transfer and rated adult care as better or no different to paediatric care for services and support offered. The proportion self-managing care was generally higher in adult care but there were some areas that might be improved, such as naming one's HIV medication, most recent CD4 and VL, and possible side effects of ART medication. Interestingly, neither being able to name HIV medication or being able to recall the number of pills taken daily was associated with better adherence.

Other studies of young people's own views on their transition experiences are from five high income countries (HIC) (UK,[8-11] Australia,[10] Canada,[12] the USA[13, 14] and France[15]) and seven low and middle income countries (LMIC) (Kenya,[16] Uganda,[17] Brazil,[18] Dominican Republic,[19] Jamaica,[20] Thailand,[21, 22] Cambodia[23]), with one being conducted across different income settings,[24] and the larger studies' findings, particularly from HIC due to comparability, are summarised here. In one study in 2008-9, self-reported satisfaction of health care experiences and preferences of 21 young people with PHIV attending a new UK outpatient transition service was compared to 39 young people attending a well-established diabetes transition service in Australia.[10] Encouragingly, reported satisfaction of young people with PHIV attending the new service was as positive as those attending the diabetes outpatient service. Both services also scored highly on patients feeling they were allowed enough time to discuss problems, being treated as a an individual, feeling comfortable discussing their health concerns, and being encouraged to develop more independence and control of their care. Both transition models adopted an age-appropriate approach and were flexibly paced to the individual needs of the young person. A follow-up study of 51 patients attending the UK clinic in 2014 confirmed the high levels of patient satisfaction on the same themes, and patients also had high praise for the clinic staff.[8] This study adds evidence that an engaging and empowering transition service is crucial for young people to maintain their health, and it may be relevant for young people with other chronic illnesses.

In the Canadian study of 25 patients, most felt that the age of 18 was too young for transition, and 18 is older than the median age of transfer in our study (17 years for direct care transfer and 16 years for shared care transfer).[12] Suggestions for improving the transition process included allowing young people to maintain connections with non-medical members of the paediatric team, rotating appointments between the adult doctor and paediatrician until bonds were established with the adult doctor, and being given more information on adult care.

The study from the USA looked at the congruence of transition perspectives between 18 young people and their guardians, and found varying expectations about the level of involvement of young people in transition decisions.[13] However young people and guardians shared the perception that transition would give young people more responsibility and decision-making power. A further study by the same authors, of 40 young people and 17 guardians, reported that young people did not know what to expect of transition, and highlighted the importance of improved communication between providers and patients to encourage preparation.[14]

The other studies, conducted in LMIC, described young people's transition experience and common transition challenges.[16-24] These included fear of abandonment, loss of peer support, negative perceptions about adult care (longer wait times, unfavourable appointment days[17] and poorer quality of care),[16, 18-20, 24] and stigma.[16, 19] Many young people however did have positive transition expectations. Enabling factors included creating supportive family, peer and healthcare environments,[18, 23] maturity, financial security, early preparation, transitioning as a group and staying at the same health care centre after transition.[16, 17] Adolescents frequently expressed the desire for a holistic transition process, including an early introduction to the idea of transition, the need for more time to become adapted to the transition process, an established transition program, involvement in decision-making, contact with the adult team before transition, and adolescent support groups in adult care.[16-20, 22] These recommendations are reflected in the CHIVA guidelines on transition for adolescents with HIV,[5, 7] and it is reassuring that clinics in our study were already following these recommended transition processes despite the guidelines coming out at the same time as our study interviews, and that most of our young people reported a good transition experience.

Our study did not investigate the health care professional's perspective on transition, although other studies have explored this. Seven studies from sub-Saharan Africa [25-31]and one from Dominican Republic [19] explored provider perspectives on transition in LMIC settings. They found that there were few LMIC national guidelines or tools to support transition and scarcely any facilities had transition protocols.[25, 28, 29] The age of transition ranged from 13-25 years; three studies reported using social signals, such as completion of secondary school and pregnancy in addition to age, to justify transition.[26-29] In HIC, one European study [32] and two USA studies [33-36] also explored providers' views on the transition process. In France, health professionals reported making a clinical care distinction between young people with perinatal HIV and those infected horizontally, and allocated varying levels of care according to need.[32] Three types of problematic situations were identified: difficulties with accepting the illness; communication problems; and problems of disorientation in the new care environment. In one USA study 58 qualitative interviews were conducted with social service and health care providers. Findings included barriers to care falling into three levels: structural, including insurance eligibility, transportation and HIV-related stigma; clinical, including inter-clinic communication, and resource and personnel limitations; and individual, including adolescent readiness to transition and developmental capacity. Four key factors were identified as imperative to transition success: clinical outcomes such as adherence and viral suppression; patients being able to self-manage their care; patients taking responsibility for their overall health; and patients feeling connected to the adult clinic. Strategies to help generate this connectedness (e.g. adolescent clinic staff attending first adult care appointment) and approaches to evaluating longer term outcomes, such as data sharing, were recommended. In another USA study where 19 professionals who provided care for children and adults with HIV were interviewed, again, behavioural indicators, including keeping appointments, adhering to medication and taking ownership of medical care, were key to successful transition.[36] These findings are reflected in our study where a higher proportion of those in adult care reported self-management for appointments, making their own travel arrangements to clinic and informing the clinic when an ART prescription was needed. However, our study findings suggest that efforts to help young people take responsibility for their overall health could be improved, as well as knowledge of ART, possible side effects and CD4 and VL values.

This study has a number of limitations. Firstly, most responses in the transition questionnaire required self-report, which introduces the possibility that participants may have given false or inaccurate responses. However we aimed to minimise this by ensuring anonymity of questionnaires. Secondly, there may have been issues of recall bias for some of the older young people who were answering questions about their transition experience several years ago. Thirdly, most of our participants were recruited from HIV outpatient clinics in hospitals, therefore we may not have reached those not accessing care who may have had a different transition experience. However, we also recruited in the voluntary sector, and a comparison of the demographic characteristics of PHIV included in our study compared to the wider cohort of adolescents with PHIV in the UK and Ireland suggested no major differences.[4]

Overall, the majority of participants in our study reported a good transition experience, which is reassuring and suggests clinics and healthcare teams are doing it well. However there are some areas that need improving, such as being able to name ART, possible side effects and understanding CD4 and VL. This is not the first wave of UK adolescents transitioning, so lessons have been learnt from the first cohorts of young people who may have had particular challenges, including later ART start, exposure to sub-optimal ART regimens, treatment failure and other comorbidities, particularly in LMIC. Although transition models may vary, common themes to a successful transition emerge, such as youth-friendly services, ongoing communication between providers and patients, early integration of paediatric and adult services, and a holistic individualised approach.[37] Transition from paediatric to adult services occurs at a time when adolescents living with HIV are managing many changes associated with adolescence and therefore it is vital that services support them so they have a good transition experience but also so they can improve managing their health within the context of their wider lives.

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All authors substantially contributed to the concept and design of this paper. KS, MLP and KR acquired the data, and HC, LT and EC did the analysis. KS drafted the article. All authors revised the article for important intellectual content, approved the final version for publication, and are accountable for all aspects of the work.

Figure 1: Participants' rating of adult care compared to paediatric care

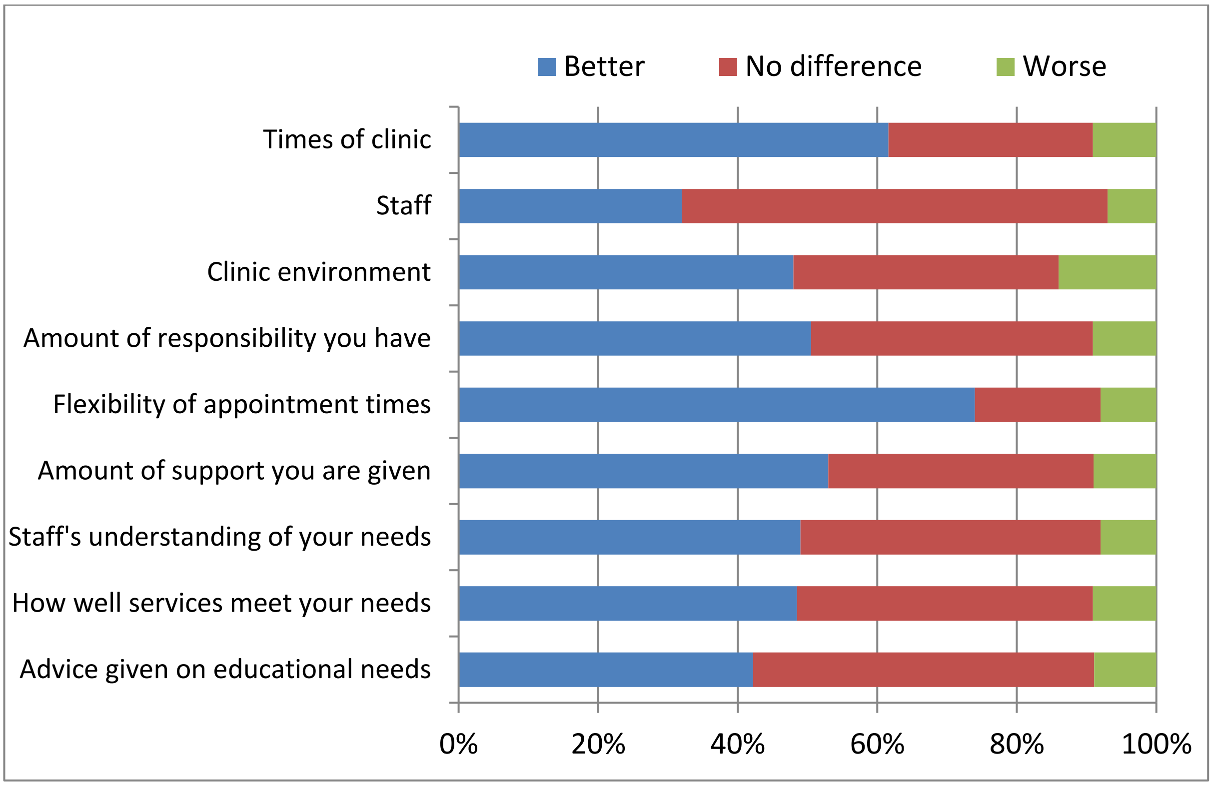

Figure 2: Participants' self-management of care

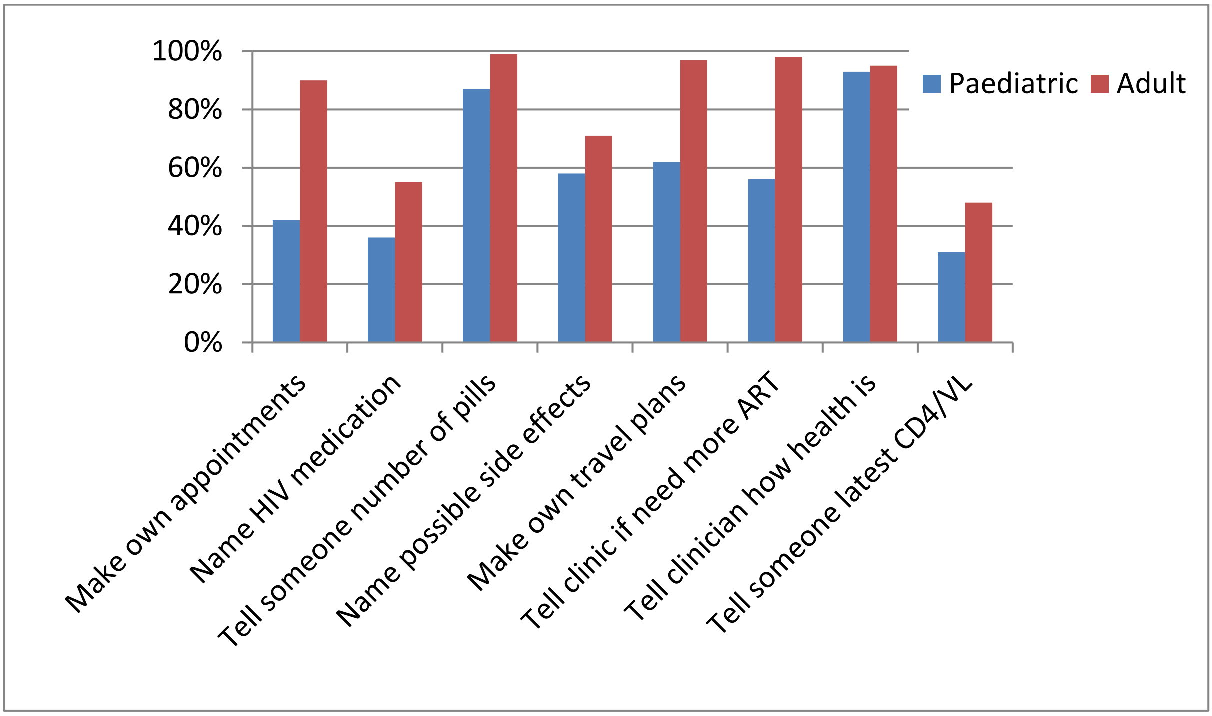

Table 1: Participant characteristics

	Type of care		Total
Characteristic	Paediatric (n=45)	Adult (n=87)	(n=132)
	No. (%) or median [IQR]		
Male sex	20 (44%)	28 (32%)	48 (36%)
Age (years)	16 [16, 17]	20 [19, 22]	19 [17, 21]
Black ethnicity	35 (78%)	77 (89%)	112 (85%)
Born outside UK or Ireland	25 (56%)	41 (47%)	66 (50%)
Occupation:			
Full-time education	40 (89%)	51 (59%)	91 (69%)
Employment	3 (7%)	26 (30%)	29 (22%)
Not in education or employment	2 (4%)	10 (11%)	12 (9%)
Death of one/both biological parents	14 (32%)	29 (36%)	43 (34%)
Last time attended clinic:			
≤6 months ago	43 (96%)	83 (95%)	126 (95%)
>6 months ago	2 (4%)	4 (5%)	6 (5%)

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