"I LOOK FORWARD. I FEEL INSECURE BUT I AM OK WITH IT". THE EXPERIENCE OF YOUNG HIV+ PEOPLE ATTENDING TRANSITION PREPARATION EVENTS: A QUALITATIVE INVESTIGATION.

Tomas Joseph Campbell, Beer Hannah, Rebecca Wilkins, Ella Sherlock, Anna Merrett, Jayne Griffiths

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Transition programmes which prepare young people with HIV to manage the medical, social and psychological consequences of the condition can provide clinical benefits for both young people and their families. The London based Looking Forward Project (LFP) is embedded within a National Health Service HIV family clinic. The project uses a group work approach and aims to equip HIV+ young people over the age of 12 years who know their status with the emotional, psychological and behavioural skills necessary to face the challenges of living with HIV. This small scale qualitative study investigated the experience of attendance, explored factors which facilitated participation in the groups and investigated the impact on their lives as a result of participation. Participants reported that the LFP events were educational but different to school-like activities, being with other young people reduced isolation and that receiving a voucher was an incentive to attend. Participation was facilitated through family support. Attendance at the LFP facilitated a positive attitude towards medication and hope for the future.

Introduction

HIV+ children and young people are living longer and healthier lives (Prime et al, 2004). HIV services face the challenge of developing transition mechanisms from paediatric to adult-centred care. Adult HIV services have little experience of dealing with the complex life issues that young people bring (Miles et al, 2004), parents of HIV+ young people have understandable concerns about their child's ability to cope with increased self-management, leakage of confidentiality, and HIV related stigma still exists (Ostrom et al, 2006; Rotherham-Borus et al, 2005; Wilkins et al, 2007). These issues can make it difficult to achieve a planned transition process to facilitate good clinical outcomes.

The transition process

Transition is the "purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented health care systems" (Blum et al, 1993: pp 570) and is a *process* not an administrative event (McDonagh, 2000). The transition process aims to help the young person acquire some of the emotional and psychological skills required to help them cope effectively with their condition over the course of their lives (Weiner et al, 2007; Lewis-Gary, 2001; Viner, 1999: Uzoebo et al, 2008; Rosen et al, 2003).

There is evidence that good transition programmes can provide clinical benefits including improved follow-up (Rettig & Athreya, 1991), better disease control and improved documentation of transitional issues (Cameron, 2001; Robertson et al, 2006). Poorer clinical outcomes have been identified in other disease areas (e.g. diabetes, juvenile arthritis, cancer) where the process of transition was not emphasized including poorer out-patient clinic attendance, poorer adherence to treatment and increased morbidity and mortality (Prime et al, 2001; Martinez et al, 2000; Kipps et al, 2002; Weiner et al, 2007). Within

the HIV context, however, psychosocial support and preparation for self-management for HIV+ young people is rare (Bitsindou et al, 2007; Lesch et al, 2007).

In the UK there are 848 HIV+ young people aged between 10-18 years who are transitioning or will need preparation for transition. Of this number 611 receive their care in London (National Study of HIV in Pregnancy and Childhood, 2009)

Family and cultural factors which may affect the transition process

Most vertically acquired HIV+ young people in the United Kingdom (UK) are of African origin (Judd et al, 2007) and live in families which face multiple challenges e.g. immigration issues, housing, employment and educational difficulties, stigma and discrimination (Green and Smith, 2003; Waugh, 2003). Many parents struggle with HIV disclosure to their children as they fear their children will be psychologically damaged by the news (Waugh, 2003; Weiner, 1996; Murphy, 2008). As a result families may feel unable to take on new issues (e.g. transition issues) which are potentially distressing (Wilkins et al, 2007). These factors may complicate the process of transition.

The Looking Forward Project

The London based Looking Forward Project (LFP) was created in 2004 and is embedded within a National Health Service HIV family clinic. The LFP provides a structured approach to transition in which topics such as medication adherence, romantic and sexual relationships and the development of coping strategies are addressed (Wilkins et al, 2007).

The LFP organises regular and structured events at four month intervals aimed at providing young people with both information about HIV issues and the opportunity to acquire new skills to manage difficulties and challenges. Young people over 12 years who know their diagnosis are invited to attend

with parental consent. In 2007 there were nineteen young people attending the family clinic who were eligible to participate. All were invited to each event.

The LFP is led by clinical psychologists and an HIV clinical nurse specialist but includes contributions from a specialist pharmacist, specialist midwife, a drama specialist and the local young peoples' sexual health team. Each group meets for one day three times yearly during holidays (e.g. Easter and summer holidays, October break) in a non-clinical environment (a church hall). Participants are invited to lunch and also receive a £15 voucher at the end of the event. Questionnaire evaluation indicated that following attendance, knowledge levels about HIV increased as did levels of comfort in talking to health professionals (Campbell et al, 2008).

The project uses a group work approach in which different teaching and facilitation styles are employed depending on the issue e.g. teaching about medication uses both a didactic approach and a knowledge quiz in which misinformation is corrected and inadequate information is discussed more fully. Disclosure of HIV status to friends and romantic partners is addressed by using group discussion and drama techniques. Older members have led discussions about their experience of disclosure and younger members have had the opportunity to ask them questions about the experience. Sexual health needs are addressed e.g. demonstrations of condom and lubrication use, transmission of sexually transmitted infections is explored and discussed and participants practice placing condoms on plastic models.

Aims of the study

This small scale study aimed to investigate participants' experiences of the events, the factors which facilitated attendance and the impact on their lives as a result of participation using a qualitative thematic approach (Braun & Clarke, 2006).

Methods

All participants who had attended an event in 2007 (n = 11) were sent a letter explaining that the LFP team wished to evaluate their experiences of the LFP.

Six participants responded. Interviews were conducted by two interviewers unknown to the participants in order that as wide a range of responses as possible could be facilitated. Participants were interviewed once by a researcher.

To maximise study participation, participants were given a choice about how the interview was conducted i.e. by telephone or in person at their next clinic appointment. This recruitment approach was used as it was hard to agree with participants a time and venue to conduct the interviews because participants had competing demands on their time (e.g. homework, socialising, sport). No more than two months had elapsed between attendance at the event and study participation.

The interview schedule comprised four questions: How did participants learn about the event and what helped them to attend; what was their experience of participation in the event and what was the impact on their lives as a result of attending?

The conversations were transcribed verbatim. Initially the transcripts were analysed separately by two authors (non-interviewers) for commonly recurring themes. These themes were then collaboratively reviewed and refined in line with guidelines described by Braun & Clarke (2006). To ensure rigour and trustworthiness interviewer-debriefing took place, the themes were reviewed with the interviewers to ensure they were grounded in the data and the study design, interview items and findings were discussed with clinical colleagues.

Participants

Three males and three females participated in the evaluation. They ranged in age from 13-15 years. Demographic information is displayed in table 1. All participants were of African ethnicity and had acquired HIV vertically. All names are pseudonyms.

Table 1 Participant details

Name	***Philip***	***Justine***	***Rita***	***Max***	***John***	***Ellen***
Gender	Male	Female	Female	Male	Male	Female
Age	14	13	14	13	15	14

Results

Themes were developed around the four main interview questions. With regard to information about the event and factors facilitating participation, themes which emerged were the importance and meaning of a personally addressed invitation, practical support, and the role played by the offer of lunch and a voucher as an incentive to attend. Themes which emerged from the question about their experiences of the events were that being with other young people was helpful but questions emerged which might not be raised in other settings (particularly about disclosure). In terms of the impact of attending, participants emphasised an increased acceptance of medication and that information and education helped in the coping process. They also expressed optimism for the future, although this was tempered with acknowledgement of challenges. Although the themes are presented as discrete entities it is important to note that there was overlap amongst them.

How did participants learn about the event and what helped them to attend?

Acknowledging both independence and the need for support

Receiving a personally addressed invitation letter and event programme was identified as important by several participants and may have reflected a growing sense of independence and readiness to play a bigger part in their own health care. However, attendance at the event also required support and affirmation by family and/or health professionals and practical help e.g. dropping off the young person at the venue.

*"I got a letter and there were instructions. I think I opened it, I'm not sure. I had heard about it before from Mum. I'm not sure how Mum heard about them. I decided to go. I got the bus and then got lost so I went home and Mum dropped me off. I never knew (*name of venue*) was in the centre (*of town*)" (Max, 13).*

Receiving lunch and vouchers encouraged attendance

Several participants were explicit that incentives played a key role in encouraging attendance. Three mentioned the importance of receiving a voucher at the end of the event, as well as lunch at a local restaurant. The lunch also offered a break from what could be an emotional experience, and taking lunch with the LFD facilitators also emphasized that the LFP was not like school.

*"I really enjoyed it…getting together and doing activities, running around, moving around…. N**** (*the restaurant*)" (Rita, 14)*

Making other choices

However, there were competing priorities during school holidays and attendance at the LFP was not always a priority.

"My Dad told me about the day. I have been to a few now but I had to miss one because I was busy doing a dance show but I would have come otherwise" (John, 15).

What was their experience of participation in the event?

Activities make the process interesting

The importance of activities was emphasised. Activities brought energy, fun and stimulated interest in what might otherwise be an unsettling experience.

"It was really good. I didn't expect it to be. I thought it would be just talking. There was (sic) activities, acting, about HIV, Mum telling…That was kind of new" (Philip, 14)

The activities and games also differentiated the events from school experiences. The approach was a mixture of didactic teaching, questions were encouraged and participants were free to get snacks when they wished.

"I liked that you could just go and get a drink. It would have been like a school trip otherwise. They got to know us, not like teachers" (Philip, 14).

Being with others who are the same is helpful

Participants remarked that it was helpful to be with other HIV+ young people. Most participants mentioned that it was helpful being part of a group in which difficult explanations about status were not required and where there was no secrecy.

"I enjoyed being with people I already know. It was a good thing meeting people because that's what you do in life. It's good to meet new people I didn't know before. Now that I'm a teenager I get stroppy and stuff. When I found out I was upset. I felt alone, I felt upset. When I started attending the sessions I met others with the same condition. I felt part of a group. Now I know there are others with the same condition" (Rita, 14)

Focusing on HIV can be hard

Whilst participants found it helpful to be with other HIV+ young people, they sometimes found an explicit focus on HIV difficult. They tended to speak about their own and others' status in an oblique manner and often avoided using the term "HIV". This may indicate that there is a discomfort in naming the disease

"I don't like talking about it (HIV)…it's hard" (Max, 13)

The complex issue of disclosure

Participants raised the complexities surrounding disclosure that they faced on a daily basis. In particular, they were concerned about the impact of the disclosure of their status on their romantic relationships.

"Trying to go out with someone...you might have to tell your girlfriend" (Philip, 14)

One participant identified a strategy for disclosure based on the building of mutual trust.

"…it made me consider what I would do if I was in a relationship. Would I tell them? I suppose not. Keep it cool because you don't want to bring up the situation. Learn to trust them, love them. Eventually it comes out in the open. Take time. You just can't tell them. Your condition is a secret because you

need to learn to trust them. If you just fall out there's no point telling them then the relationship is over" (Rita, 14)

Participants also talked about their fear of unintended/unwanted disclosure of their status, for example, when medications were taken in atypical environments.

*"Just taking them and having to take them (meds) somewhere (*stressed tone*). You have to remember to carry them. When I visit my sister my meds are quite big. It's OK now but in the future I suppose I might have to find someone and someone might find out. What will they think of me?" (Rita, 14)*

What has been the impact on their lives as a result of attending?

Pro's and con's of taking medication

Taking medication was a major theme for participants. Several participants noted that as a result of attending they accepted that medication was a part of their lives and something they had to cope with. They felt that the educative aspect of the LFP helped them to understand the health benefits of medication, and tended to stress these rather than side-effects or adherence difficulties.

"I feel alright. I know I have to be careful and be healthy, but I have to live with it forever so need to just get on with it. I feel alright about taking medication as I know it's just something I have to do. I have to accept it and it's not too bad at the moment as I only to have to take three" (John, 15)

An uncertain but hopeful future

Participants had hope for the future even though some acknowledged that there might be difficulties especially in regard to disclosure of HIV status to romantic/sexual partners. This often overlapped with the theme of the importance of meeting other HIV+ young people to share experiences and being reassured that their experience was not unique.

"I feel happier and know that I am not alone and I am not afraid anymore. I feel less scared now. I feel not as worried about the future as I did before. I know that I am not the only one with it and that I can do most things that other people can do but just need to be careful. I know that I have somewhere to talk about things, although I can talk to my aunt, it is good to talk to people my age as well and be open about things. I feel better about managing and looking after myself in the future, but know that it will depend on the situation" (Ellen, 14)

"I look forward. I feel insecure but I am OK with it" (Philip, 14)

Discussion

This small scale study focussed on factors that facilitated participation in the programme and the impact participation had on young peoples' lives. This is a small sample even for a qualitative study and consequently the results should be interpreted cautiously. However, both the project itself and the results have been encouraging both in the way participants have evaluated each event (Campbell et al, 2008) and the benefits they state they have derived from participation as reported in this paper. Reduced isolation and a stimulating fun space in which to address common issues emerged as important benefits for participants although they were well aware of the challenges they faced for the future particularly with regard to disclosure of HIV status. A balance of recognising that there will be challenges to face in life ahead and the ability to remain optimistic and hopeful seems to characterise many of the responses reported here. Indeed, the title of this study was inspired by this quote: *"I look forward. I feel insecure but I am OK with it" (Philip, 14).*

It seems that receiving a personally addressed letter outlining the programme was important but participants also needed practical help from parents/guardians to attend. This may indicate that participants were more likely to come from families who are willing and able to support attendance both emotionally and practically. However, of the nineteen young people eligible to attend eleven actually did so. We do not know why the other eight eligible young people did not attend but it could be that they lived in families who were coping less well with HIV. All participants were ethnically African and many African families in London face challenges other than HIV (Green & Smith, 2003) which may affect their capacity to identify with, and provide for the transition needs of their HIV+ young person. Parents may benefit from targeted therapeutic interventions to help develop their coping abilities both with regard to their own HIV issues and those of their HIV+ young people. Further work may need to be developed within the family clinic to identify and

support families who may be struggling. However, this would have to be balanced with families' right to privacy and respect for their wishes if they do not want their young person to participate. Alternatively, other eligible young people may not have attended as they and/or their families may have seen the events as less relevant to their personal circumstances or may have been concerned that attendance placed undue emphasis on HIV status rather than living a more "normal" life.

Participants indicated that the activities were an important component of the programme. Activities differentiated the LFP events from school experiences and promoted an atmosphere that was collaborative, encouraging and enjoyable. Taking lunch at the local restaurant seemed an important incentive as was receiving a voucher at the end of the day. Participants understood the importance of taking their medication and generally emphasized the benefits rather than difficulties. However, taking medication may have also served to emphasize difference from family members or friends and increased concerns about unintended disclosure.

Being with others who were HIV+ was both comforting and difficult. It was reassuring to know there were others who shared similar experiences. Being open and not having secrets provided hope and fun. However, it could also be painful to talk about HIV especially in relation to potential romantic/sexual partners. All participants were at the age at which sex and sexuality were important issues and they were aware of the difficulties that disclosure of their status might pose to potential partners. Receiving positive, encouraging and normalising messages about their sexuality and sexual behaviour is important in order that positive young people do not grow up with negative feelings about themselves, sex and sexuality (Fielden et al, 2006; Campbell et al, 2009). Interestingly, participants did not comment on the specific sexual health components of the LFP which included experience of handling condoms and lubrication and the exploration of sexual negotiation strategies with potential partners. Perhaps participants were not sexually active at the time and sexual health training had reduced salience and applicability for

them. It may well be that older participants found this training to be more useful. However, participant embarrassment may also explain lack of reference to the LFP sexual health components as young people tend to be uncomfortable about such discussions with older people (Burgess, Dziegielewski & Evans Green, 2005). It may be useful to repeat this study in the future with a wider age range to assess the utility of these specific interventions.

Participants were a self-selected group and this may have biased responses. However, six of eleven LFP attendees participated in the study which is a good response rate and lends reliability to the results. A larger sample would have addressed potential bias issues but because it was difficult to arrange suitable times and venue to conduct interviews it was not possible to recruit more participants within the study timeframe. It is also important to acknowledge the possible impact of interviewer bias as the interviews were conducted by two separate researchers.

Conclusion

The LFP will continue to develop and change in line with the needs of participants and this small scale study has provided some evidence that this is a useful approach to meet the transition needs of HIV+ young people. However, the development of pre- and post-evaluation tools and a larger qualitative study focused on particular aspects of the project will be important to implement in order to further explore the effectiveness of the intervention.

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References

Bitsindou, P., Nzounza, P., Diafouka, M., Sibillle, B., Tran-Minh, T., Mouala, C., Adam, G., Mooney, M. & Mattei, J-F. (2007). Need for dialogue in talking to children and adolescents living with HIV, Abstract no. 155, *AIDS Impact Conference,* Marseille, France, 1-4 July.

Blum, R., Garrell, D., & Hodgman C. (1993). Transition from child-centred to adult health-care systems for adolescents with chronic conditions. A position paper for the Society for Adolescent Medicine, *Journal of Adolescent Health*; 14, 570-6.

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101.

Burgess, V., Dziegielewski, S.F. & Evans Green, C. (2005). Improving comfort about sex communication between parents and their adolescents: Practice-based research within a teen sexuality group. *Brief Treatment and Crisis Intervention*, 5, 4, 379-390.

Cameron, J.S. (2001). The continued care of children with renal disease into adult life. *Pediatric Nephrology*, 16, 8, 680-685.

Campbell, T., Beer, H. & Wilkins, B. (2008). Group work with HIV+ teenagers to facilitate transition to adult services and avoid loss to follow –up. *HIV Medicine,* 9 (Suppl 1), 45.

Campbell, T., Beer, H., Wilkins, R., Parrett, N. & Jauslin, L. (2009). "Sex, love and one-night stands: getting the relationship you want": Evaluation of a sexual health workshop for HIV+ young people. *Education and Health*, in press.

Fielden, S.J., Sheckter, L., Chapman, G.E., Alimenti, A., Forbes, J.C. Sheps, S., Cadell, S. & Frankish, J. C. (2006). Growing up: Perspectives of children, families and service providers regarding the needs of older children with perinatally-acquired HIV. *AIDS Care*, 18, 8, 1050-1053.

Green G. & Smith, R. (2003) The psychosocial and health care needs of HIV-positive people in the United Kingdom: a review. *HIV Medicine,* 5 (Suppl. 1), 5-46.

Judd, A., Doerholt, K., Tookey, P., Sharland, M., Riordan, A., Menson, E., Novelli, V., Lyall, E.G.H., Masters, J., Tudor-Williams, G., Duong, T & Gibb, D (2007). Morbidity, mortality, and response to treatment by children in the United Kingdom and Ireland with perinatally acquired HIV infection during 1996-2006: Planning for teenage and adult care. *CID*, 45, 7, 918-924, 1 October.

Kipps, S., Bahu, T., Ong, K., Ackland, F.M., Brown, R.S. & Fox, C.T. (2002). Current methods of transfer of young people with type 1 diabetes to adult services. *Diabetes Medicine*, 19, 649 – 54.

Lesch, A., Swartz, L., Kagee, A., Moodley, K., Kafaar, Z., Myer, L. & Cotton, M. (2007). Paediatric HIV/AIDS disclosure: towards a developmental and process-oriented approach, *AIDS Care*, 19, 6, 811-816.

Lewis-Gary M.D. (2001). Transitioning to adult health care facilities for young adults with a chronic condition. *Pediatric Nursing*, 27, 5, 521-525.

Martinez, J., Bell, D., Camacho, R., Henry-Reid, L.M., Bell, M. & Watson, C. (2000). Adherence to antiviral drug regimes in HIV-infected adolescent patients engaged in care in a comprehensive young adult clinic. *Journal of the National Medical Association*, 92, 55-61.

McDonagh J.E. (2000). The adolescent challenge. *Nephrology Dialysis Transplantation,* 15: 1761-1765.

Miles, K., Edwards, S. & Clapson, M. (2004). Transition from paediatric to adult services: experiences of HIV-positive adolescents. *AIDS Care*, 16, (3), 305-314.

Murphy, D. A. (2008). HIV-positive mothers' disclosure of their serostatus to their young children: A review. *Clinical Child Psychology and Psychiatry*, 13, 105-122.

National Study of HIV in Pregnancy and Childhood (2009). Summary data, January. http://www.nshpc.ucl.ac.uk/ (accessed Feb 27).

Ostrom, R.A., Serovich, J.M., Lim, J.Y. & Mason, T.L. (2006). The role of stigma in reasons for HIV disclosure and non-disclosure to children. *AIDS Care,* 18, (1), 60-65.

Prime, K.P., Jungmann, E.A. & Edwards, S.G. (2004). Decline in mortality in children with HIV in the UK and Ireland. *BMJ*, 328, 524 (28 February).

Prime, K.P., Sethio, G., Dean, G.L., Fox, E., De Ruiter, A. & Taploe, C.B. (2001). Teenagers and HIV: What's the problem? *HIV Medicine*, 2, 11.

Rosen, D. S., Blum, R.W., Britto, M., Sawyer, S.M. & Siegel, D.M. (2003) Transition from child-centred to adult health care for adolescents and young adults with chronic conditions. Position paper for the Society for Adolescent Medicine, *Journal of Adolescent Health*; 33, 4, 309-311.

Rettig, P. & Athreya, B.H. (1991). Adolescents with chronic disease: transition to adult health care. *Arthritis Care Research*, 4, 174-180.

Robertson, L.P., McDonagh, J.E., Southwood, T.R. & Shaw, K.L. (2006). Growing up and moving on. A multicentre UK audit of the transfer of adolescents with juvenile idiopathic arthritis from paediatric to adult centred care. *Annals of Rheumatic Disease*, 65, 74-80.

Rotherham-Borus, M.J., Flannery, D., Rice, E. & Lester, P. (2005). Families living with HIV. *AIDS Care*, 17, (8), 978-987.

Uzoebo, V., Kioko, M. & Jones, R. (2008). Deconstructing youth transition to adulthood services: Lessons learned from the VISIONS program. *Vulnerable Children and Youth Studies*, 3, 1, 37-41.

Viner, R. (1999). Transition from paediatric to adult care: Bridging the gaps or passing the buck? *Archives of Childhood Diseases,* 81, 271-275.

Waugh, S. (2003). Parental views on disclosure of diagnosis to their HIV-positive children. *AIDS Care*, 15, 2, 169-176.

Weiner, L., Zobel, M., Battles, H. & Ryder, C. (2007). Transition from a pediatric HIV intramural clinical research program to adolescent and adult community-based care services: Assessing transition readiness. *Social Work Health Care*, 46, 1 1-19.

Weiner, L.S., Battles, H.B., Heilman, N., Siegelman, C.K. & Pizzo, P.A. (1996). Factors associated with disclosure of diagnosis to children with HIV/AIDS. *Pediatric AIDS & HIV Infection*, 7, 5, 310-324.

Wilkins, R., Campbell, T. & Beer, H. (2007). Preparing HIV-positive young people for the challenges of adult life: a group work approach. *AIDS & Hepatitis Digest,* 119, May, 1-4.