THE EFFECT OF COPING STRATEGIES ON QUALITY OF LIFE OF YOUNG PEOPLE LIVING WITH PERINATALLY ACQUIRED HIV

Rebecca Mbewe
Anne Manyande
Introduction

Some basic facts:

• The first vertical transmission reported in the UK was in 1985.

• Since then a total of 2,101 of transmissions have been identified.

• Pregnancy rates in women living with HIV have increased significantly.

• Terminations have also reduced drastically due to interventions (e.g. C-sections, not breastfeeding etc.) (HPA, 2012)
Background

• Without Highly Active Antiretroviral Therapy (HAART), approximately 15 to 30% of infants contracted the virus. An additional 5 to 20% became infected through breastfeeding (De Cock et al, 2000).

• Consequently, there has now emerged a first generation cohort of young people who were infected perinatally and are having to deal with the challenges of living with HIV (Dowshen & D’Angelo, 2011).

This begs the question:-

“HOW DO THEY COPE WITH LIVING WITH HIV?”
Previous Research (USA, Swiss, SA, Brazil, SA)

- Coping strategies of adolescents living with HIV: disease-specific stressors and responses (Orban et al, 2010)
- Coping with an HIV infection (Pierre-André et al, 2010)
- Ways of coping with AIDS: opinion of mothers with HIV children (Da Silva et al, 2008)
Available data based on the actual experiences of the youth living with HIV is limited

(Dowshen & D’Angelo, 2011)
Aim of Study

• To explore and identify from a subjective perspective, the coping strategies employed by young people living with perinatally acquired HIV and the effect this has had on their quality of life.
### Characteristics of Participants

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<th>Participant Pseudonyms</th>
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<th>Treatment</th>
<th>Education/Employment</th>
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Method

Design
• A qualitative approach was adopted using semi-structured interviews.

Participants & Procedure
• A heterogeneous group of seven individuals receiving care from a London based HIV clinic and aged between 18 -25 years were recruited to participate in the study.

• The interviews were tape-recorded, transcribed and analysed using Interpretative Phenomenological Analysis (IPA)(Smith & Osborn, 2008).
Findings

• Three main themes with sub-themes emerged:

(i) unhealthy style of coping which focuses on stigmatisation, discrimination, denial, fear of disclosure and non-adherence to treatment

(ii) healthy coping that seeks support from family, friends, peers and health care workers; and finally

(iii) embracing positive attitudes to life and taking opportunities.
Findings (continued)

• Unhealthy coping (Denial, Fear of disclosure)

“I just didn't get to terms with it. I just left it there, I just forgot about it so... but only last year I started to think about it - right, this is me, this is... you know?”

Jazz

“I found it really, really hard. I felt really isolated for a long time - I thought I can't talk to anyone.”

Steve
Findings (continued)

• Unhealthy Coping (non-adherence to treatment)

“Obviously before most people are on their treatment and they don’t know what it’s for, they’ll take it, their mum or dad tells them to take it and that's that. And erm... as soon as they find out, their whole attitude changes, they think..., I'm not depending on this, you know...? If I'm gonna die, I'm gonna die, so I'm not going to take medication anymore and they stop and that was one thing that I'd done. Because I used to think it was so fun and cool like at 11 to be having, you know... I was the only one in my house... well me and my mum taking our medicine, and my sister would be like.. oh why aren't I doing it. And I just found it really fun until I found out.. I thought, well hold on... I'm taking it because of that?! I was told I was taking my medication for pneumonia and I used to sit there and be like oh I'm so ill, off school and PE and all these things, I had all excuses and I think as soon as you find out that it's HIV it's just..., everything just changes and you don't to take it anymore, because it’s like depending on a pill to keep you alive and you don’t want to do that as a teenager... you just want to think... oh I just wanna be like my friends. And you go to a sleepover or whatever and you've got to carry this box around with you that you've got to hide in your bag and it’s just this whole situation. Obviously now, it's not an issue, I take it. It's like second nature.”

Josie
Findings (continued)

• Healthy coping (Support)

“The support I received when I first found out, I was diagnosed, erm... was my best friend. I had no idea of his status. Like I came home one day and he was there with another friend and my partner at the time – they asked me, oh, how did your test go because they knew I had a blood test and I just said – I’m positive. It just came out. And they were all like, ooohhh!... Like they felt sorry for me and I was like... whatever... And then they all left the room. My best friend stayed and he was like, oh it’s okay because I’m positive too.”

Koko
Findings (continued)

• Healthy coping (Disclosure)

“...I just disclosed. I wouldn’t say support necessarily, I’ve just had people who didn’t respond negatively when I disclosed to them. I am quite fortunate that I have disclosed to a lot of people and haven’t had a negative response yet. So, I think that’s support in itself. I also think that my brother has always been a big support. I mean he will fight anyone that says something wrong so...”

Chantel
Findings (continued)

• Embracing attitudes

“...getting to meet other people... that you can meet your best friend in these places. You know like lets say... you go to university and you meet your best friend or meet your husband or whatever... I think that's... I didn’t go to uni - I will never go to uni but this is like my uni experience with these lots.

Like I met (ref to Jazz) through the work that I am doing now and I think obviously... if I wasn't positive, I wouldn't be part of (Name of organisation Kate works for), I wouldn't be fulfilling my dreams. I have always wanted to be a youth worker, but to combine being a youth worker and doing something I am so passionate about... that's just.... Yeah... that's a major positive - that's me.

Kate
Findings (continued)

• Taking opportunities

“I’ve used HIV to my advantage. Like, I’ve met Heads of State. I’ve worked in some of the biggest companies in the world, not HIV related, I’ve met some really cool people, met some really cool friends that I really like....to me essentially, my life... HIV has defined my life but it’s something that has catapulted it into a new atmosphere, a new stratosphere because I wouldn’t have done, as it was said here, I wouldn’t have done some of the things that I have done without it - I wouldn’t be motivated.”

Tunje
Conclusion

• Although antenatal screening in UK has drastically reduced the number of children born with HIV, the consequences of living with perinatally acquired HIV can be devastating and bring out issues that can be psychologically challenging.

• This study proposes that seeking support is a major step in assisting these individuals to receive appropriate psychological interventions that subsequently enhance their coping skills and quality of life. Coping for these young people is an on-going process.
Recommendations

• Smooth transition from Paediatric Units to Adult care

• Better communication and involvement in the decision making process between the youth, their parents/carers and health care professionals

• The health care setting for routine check-ups to be user-friendly

• Funding for continuous peer support
References


United Kingdom new HIV diagnoses to end of December (2011). *Health Protection Agency Centre for Infections, Health Protection Scotland and UCL Institute of Child Health*.


Thank you.

QUESTIONS?