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"To be HIV positive is not the end of the world": Resilience among perinatally infected HIV positive adolescents in Johannesburg

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ABSTRACT

Background: Resilience, or positive adaptation to challenging situations, has potential to improve health outcomes for high risk populations. Resilience may be particularly important for perinatally infected HIV positive adolescents, who are exposed to significant stigma, risks and stressors. Despite recognition that HIV positive adolescents show remarkable resilience in the face of adversity, little is known about how resilience occurs within this population.

Methods: The aim of this study was to identify elements of resilience in a group of perinatally infected HIV positive adolescents attending HIV clinics. In-depth interviews were conducted with 25 purposively selected HIV positive adolescents (15 female, 10 male) between the ages of 13–19 years in Johannesburg. Data were analysed in NVIVO 10 using a thematic approach to coding.

Results: Despite marked stressors in the lives of these adolescents, a high degree of resilience was described. Characteristics of resilience in this group included a pertinent set of beliefs, including a belief in fate and recognition of personal strength as a consequence of managing adversity. Character traits such as a pragmatic acceptance about one's life, actively taking responsibility, and a robust self-esteem were evident. Social behaviours included the ability to pursue and access adults and healthcare to meet developmental needs, having a desire to support and help others and challenging HIV related stigma. These characteristics were underscored by the capacity for self-reflection.

Conclusion: Perinatally infected adolescents, who face high levels of hardship and change, nevertheless exhibit strong resiliency beliefs, traits, and behaviours. Healthcare environments have the potential to be utilized as powerful resources in fostering resilience in HIV positive adolescents, if characteristics of adolescent resilience were integrated into current prevention and intervention programming. Resilience promotion could lead to improved health outcomes for HIV positive adolescents.

1. Introduction

'Resilience' is a relatively novel and decidedly complex concept (Ungar, 2013; Cicchetti, 2010; Windle, 2011; Masten, 2014; Zolkoski & Bullock, 2012). Although there are many different definitions of resilience, they are broadly similar and refer to the positive adaptation of people to difficult situations (Skovdal & Daniel, 2012). Resilience in the context of the HIV epidemic among children and adolescents is important, as it is well known that HIV adds a significant burden to development and that those infected are likely to suffer increased mental health problems and psychosocial stress (Betancourt, Myers-Ohki, Charrow, & Hansen, 2013; Cluver, Orkin, Gardner, & Boyes, 2012; Li et al., 2008; Mutumba et al., 2015; Sherr & Mueller, 2009; Pienaar, Swanepoel, Van Rensburg, & Heunis, 2011; Mellins & Malee, 2013).

Among perinatally infected adolescents, resilience may be a particularly important construct. There is a significant burden of HIV in adolescents with 2.1 million adolescents aged 10–19 years living with HIV globally (UNAIDS, 2013). These adolescents tend to experience enduring adversity (multiple losses and bereavement, numerous sickness and hospitalization, poor school attendance, increased poverty and exposure to violence, stigma and discrimination, disclosure challenges) as well as low levels of physical, psychological and social resources which puts them at risk for developing mental health problems (Mavhu et al., 2013; Bernays, Jarrett, Kranzer, & Ferrand, 2014;

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Lowenthal et al., 2014; Gadow et al., 2012). Perinatally infected adolescents are also more likely to struggle with adherence to treatment (Agwu & Fairlie, 2013; Kacanek et al., 2015; Lowenthal et al., 2014; Cluver et al., 2015) and may engage in unsafe sexual activity (Agwu & Fairlie, 2013; Cluver, Orkin, Boyes, Gardner, & Meinck, 2011). They are similarly at higher risk of sexual coercion and peer pressure (Kim, Fidler, & Ward, 2014), increasing the risk of secondary transmission. Indeed, nearly one-sixth of all new HIV infections are in adolescents aged 15–19 years (UNICEF, 2013) making this age group the most vulnerable incident infection population in South Africa (Shisana et al., 2014). Mitigating risk by improving mental health outcomes, particularly resilience, would be in the public health interest but more research is required to understand this construct in this population.

Studies indicate that individual characteristics, resources, and competencies — including age, cognitive capacity, sense of purpose, and belief in a positive future — contribute to resilience; supportive and accepting environmental conditions help shape resilience by mitigating the negative effects of adversity (Amzel et al., 2013). Resilience in HIV-infected adolescents is also influenced by the complex interplay between individual-level factors, family-level factors such as caregiver well being or illness, institutional-level factors such as access and engagement with health services and education, and societal factors such as stigma (Amzel et al., 2013; Betancourt et al., 2011). In addition, literature regarding HIV orphans (of which many are perinatally infected) has explored factors that contribute to their unique vulnerabilities. These are often associated with coping with the illness or loss of a parent, compounded by associated stigma, trauma and bereavement, and financial hardship (Wood, Chase, & Aggleton, 2006; Daniel, Malinga Aplla, BjØrgo, & Therese Lie, 2007; Collishaw, Gardner, Lawrence Aber, & Cluver, 2015; Li, Chi, Sherr, Cluver, & Stanton, 2015).

Masten (2001) coined the term 'ordinary magic' to refer to resilience as something nurtured by everyday resources, common to individuals, families, communities and cultures. These conventional roots of resilience suggest that resilience is not rare and that active steps can be taken to develop and sustain resilience among young people who are placed at risk by ordinary and extraordinary hardship (Theron & Theron, 2010).

Whilst progress has been made in identifying and managing risk factors for HIV positive children and adolescents, little is known about how HIV positive adolescents demonstrate resilience and how the healthcare environment can be utilized as an agent of resilience for young people. We conducted qualitative research to explore the views of HIV positive adolescents attending clinics in Johannesburg regarding resilience and mental health.

2. Methods

2.1. Participants and procedures

The study nested qualitative research into an observational adolescent study conducted in five HIV clinics serving adolescents in Johannesburg, South Africa ($n = 25/343$). Three of the clinics were hospital based; one was a community health center and one a primary healthcare clinic. All offered routine care except 1 hospital based 'flagship' clinic that offered specialized pediatric ARV services.

Participants for this analysis were recruited purposively by research counsellors familiar to the adolescent based on consent and willingness to engage in in-depth interviews. Research counsellors were trained in pediatric HIV and advanced counselling, and volunteered to participate in the research, engaging in principles of ethical research with minors. They received an additional 5 day training for this study as well as weekly debriefing and supervision throughout the course of data collection. High functioning adolescents (i.e. scoring moderate to low on standardized mental health measures indicating 'good' mental health) were chosen because their resilience was being investigated, i.e. these participants' reported difficulties and adverse life experiences did not seem to be impacting negatively on their mental health functioning. All participants reported experience of being disclosed to about their HIV-status, were on treatment for HIV and had been attending clinics for many years. A total of 62 adolescents were identified as high functioning. The 25 participants chosen from this sample characterized a range from all 5 facilities recruited from. Twenty-five adolescents between 13 and 19 yrs. (mean 16 yrs.; 15 female) were interviewed for approximately 60 min each by the principal researcher of the study using a semi-structured interview guide when they visited the clinic for their regular appointment. The interviews were recorded with participant consent and conducted in English as all participants spoke English fluently.

Participants were presumed to be infected at birth and had all lived with HIV for as long as they remembered, but it is possible that a small proportion were infected through blood transfusion or rape in childhood, although there is little data documenting this.

Participants were given a pocket sized card with active referrals for services in their neighbourhood including counselling, legal and crisis resources. Upon completion of the interview, participants received reimbursement for travel; a snack; and a gift voucher for R50 (US $4) at a local clothing retailer. These items were endorsed and recommended by the adolescent community advisory board (CAB) instituted for this research.

2.2. Ethics consideration

The South African National Health Act states that 'for health research with minors (<18 year olds), consent from a legal parent or guardian for research with children must be obtained' (Section 71, 2012). This sample was speculated to possibly not have legal guardians from whom to obtain consentAs such, the ethics committee of the University of the Witwatersrand advised approaching the court for permission to enroll participants in the study by obtaining a court order which was granted and led to full ethics clearance and permission to interview volunteers without parental or guardian consent (M130258). Where this was the case ($n = 343$) adolescents gave verbal assent and written consent to participate in the research, and all participation was sought on the basis of good clinical practice guidelines (Verma, 2013). Permission was also granted from Gauteng Provincial Department of Health, Johannesburg District Department of Health, and the research committees of facilities.

Confidentiality was maintained except where participants were at risk of significant harm, including being actively suicidal or currently experiencing abuse, in which case interviews were stopped and immediate referrals were made to child protection and health services in accordance with mandatory reporting legislation in South Africa (Children's Act, 2005). Seventeen participants were screened out of the quantitative sample for active suicidality and four participants reported historic rapes, none in the current qualitative sample. Where prior abuse or rape was no longer occurring, referrals were made to support and counselling services, again none in the current qualitative sample.

2.3. Data analysis

All interviews were transcribed verbatim in English. All identifying information regarding the participant or clinic setting was removed and transcripts were saved by a file name with no personal identifiers. Data were managed in QSR NVivo 10, a qualitative analysis software package, constructing an analytical framework of broad codes by creating a 'start list' of possible themes and building upon the research questions. Each broad code, or wide thematic basket of ideas (Creswell, 2014), was applied to each transcript and 'fine codes' were developed using an inductive approach deriving meaning from the data itself rather than imposing pre-formed ideas (Hutchison, Johnston, & Breckon, 2010). To ensure intercoder agreement, fine codes were developed by