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Quality of Life among Ghanaian Adolescents Living with Perinatally Acquired HIV: A Mixed Methods Study

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Abstract

In Sub-Saharan Africa, increasing numbers of children with perinatally acquired HIV (PAHIV) are living into adolescence. These adolescents face numerous unique challenges such as parent illness/death and years of medication use. Optimizing care for these youth requires an understanding of the factors that contribute to physical health, psychological wellbeing, social relationships, and quality of life. This mixed methods study collected quantitative questionnaire data from 40 Ghanaian adolescents with PAHIV (50% female, 12–19 years old) who received care through an adolescent HIV clinic in Kumasi, Ghana. The study also presents results from qualitative interviews conducted with 20 adolescents. Results from quantitative analyses suggested that a significant number of participants were not virally suppressed (67%) and participants reported barriers to treatment adherence, limited social support, concerns about disclosure and HIV-related stigma, limited resources, and lower than expected quality of life (QOL). Salient themes from the qualitative analyses included limited understanding of how HIV is transmitted,

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the interplay between food insecurity and treatment adherence and the need for developing safe relationships through which adolescents can discuss their illness without fear of accidental disclosure of their HIV status.

Keywords

Adolescent; HIV; Quality of Life; West Africa; Adherence

INTRODUCTION

Highly active antiretroviral therapy (HAART) has transformed perinatally acquired HIV-1 (PAHIV) infection from a rapidly progressive catastrophic illness to a chronic disease of childhood (Halloran, 2006; Judd et al., 2007; Lowenthal et al., 2014). In Ghana, roughly 24,806 adolescents are living with HIV (National AIDS/STI Control Programme, 2011), many of whom have already faced years of medication use, parent illness/death, and a host of physical and psychological concerns that are secondary to HIV and/or HIV medications. Optimizing care for these adolescents requires understanding the factors that contribute to their physical health, psychological wellbeing, social relationships, and quality of life. We used a mixed methods design to examine the challenges and protective factors for adolescents living with HIV within the sociocultural context of Ghana. Specific domains assessed included quality of life, physical/medical health, psychological wellbeing, and social relationships.

METHODS

Participants consisted of 40 adolescents with PAHIV who were receiving treatment through the Adolescent HIV clinic at KATH in Kumasi, Ghana. Eligibility criteria included: (1) 12–19 years of age, (2) perinatally acquired HIV, (3) knowledge of HIV diagnosis, and (4) willingness to consent to participation. Both the quantitative assessment battery and the semi-structured interview guide for qualitative interviews were developed by an international and interdisciplinary research team. The research protocols were approved by all of the institutions affiliated with the project.

All participants completed the quantitative assessments and a subset of 20 youth also completed qualitative interviews. Quantitative measures were administered orally in Twi, the local dialect. Oral translation of the measures from English to Twi was performed by consensus of the research team. The study coordinator and the clinic nurse administered the questionnaires. The subset of 20 who participated in qualitative interviews were purposefully sampled by the clinic director and the study coordinator to ensure that there was sufficient understanding of the challenges facing youth: thus, the sampling was skewed toward those who were reporting difficulties with managing their illness. Interviews were conducted in each youth's preferred language by a psychologist fluent in both languages, and were audio recorded with their permission.

Quantitative Assessment

Medical records from the most recent clinic visit were abstracted and included disease history, World Health Organization (WHO) clinical staging, viral load, CD4+ cell count, and provider-assessed medication adherence. Psychological well being was measured using the WHO-5 Well Being Index (Löwe et al., 2004; sample $\alpha=.84$) and the ICD-10 Major Depression Inventory (MDI; Bech, et al., 2001; $\alpha=.85$) and interpreted using established clinical cut-offs (Bech et al., 2001; Olsen, et al., 2003). Social support was measured using a 4-item instrument (emotional support, social participation, financial support, and practical support) from Bull and Mittelmark (Bull & Mittelmark, 2009). HIV-related stigma was assessed using a WHO measure comprised of 4 subscales: others' fear of contagion through casual contact, others' negative judgments of people living with HIV, enacted stigma or discrimination, and concerns about disclosing the illness to others (Makhlouf et al., 2009; α 's .53–.72). Perceived quality of life was assessed using the WHO Quality of Life – BREF (WHOQOL-BREF; WHOQOL Group, 1998; α 's .40–.87). For comparison purposes, we used age-based and regionally-based normative data collected by the WHOQOL working group (Skevington, Lotfy, O'Connell, & WHOQOL Group, 2004).

Qualitative Assessment

The qualitative interviews involved probes into 5 domains: 1) quality of life, 2) physical/medical health, 3) psychological wellbeing, 4) social relationships, and 5) intervention. Upon completion of each interview, the interviewing psychologist provided an in-depth summary of participant responses that were transcribed into English. Summaries were inductively organized and summarized with grounded theory methods focused on understanding factors identified in each of the 5 domains. A consensus approach, involving both “expert” and community action board involvement, was used for the identified structure. Content was summarized by theme using NVivo 10.

RESULTS

Demographics—Of the 40 participants, 50% were female, age range from 12 to 19 (mean = 15.53). Over half (53%) of the participants reported the death of at least one parent to HIV, with 10% losing their mother, 18% losing their father, and 25% losing both parents. Overall, 13 (33%) of the participants were virologically suppressed. For the subsample of 20 participants, 35% were female, ranging in age from 13 to 19 (mean = 15.85), with 65% reporting the loss of at least one parent (10% mother, 25% father, and 30% both parents).

Quantitative Outcomes—Descriptive statistics and effect sizes for the full sample and the qualitative subsample are presented in Table-1. Independent samples *t*-tests indicated that compared to an international age-based normative sample, the study sample reported lower QOL on all domains, Physical Health (mean difference = -2.18 [95% CI = -3.13 to -1.23]; Psychological Health (-3.26 [-4.19 to -2.33]); Social Relationships (-1.96 [-3.04 to -0.88]); and Environment (-1.69 [-2.59 to -0.79]). Compared to a regional sample of mixed ages, participants also reported lower QOL on the Physical Health (-1.98 [-3.07 to -0.89]); and the Psychological Health subscales (-2.36 [-3.43 to -1.29]), but not on the

Social Relationships (−0.36 [−1.77 to 1.05]) or Environment (−0.09 [−1.02 to 0.84]) subscales.

Qualitative Findings

Themes from the qualitative interviews are summarized in Table 2. Generally, the themes were similar to those reported for other PAHIV populations around the world (Andrinopoulos et al., 2011; Butler et al., 2009; Douaihy & Singh, 2001), but there were a few novel and salient themes that emerged from the interviews.

First, although most (65%) adolescents identified the need to take their medications, there were some surprising gaps in knowledge about how they contracted their illness. For example one adolescent reported, “It’s possible my sick mum has it and I shared her tooth brush when mine got lost.” Another stated, “I think maybe I contracted this illness when I was a toddler by playing in the sand.” Yet another stated, “Maybe I got it through barbering or shaving my hair – I am not really sure.” Second, some of the participants described how access to food affects their treatment adherence. For example, one stated, “Sometimes I want to wait until I have eaten and sometimes the time is far spent [waiting for food] and you can’t take the medication. You are forced to take it the next day.” Finally, although many adolescents talked about spending time with family and friends as a preferred coping strategy for coping with negative HIV-related emotion, most did not have someone to talk to about their illness, primarily due to concerns about unintended disclosure and stigma. When asked how the clinic could help them better manage their illness, a number identified the need and opportunities to discuss their illness without fear of disclosure. For example, one adolescent stated, “Maybe I may come and meet another youth [at clinic] and I can be open because I cannot hide anything from her since I know that person is also HIV positive – I can share without hindrance.”

DISCUSSION

The purpose of this study was to better understand the experience of PAHIV adolescents living in Ghana, with the ultimate goal of identifying ways to improve disease management and quality of life. Results indicated a need to improve a number of important areas that may help optimize HIV-related care and disease management in this population.

Compared to other studies of PAHIV adolescents, a high percentage of the Ghanaian participants were not virally suppressed (67% compared to 14–54% in international samples of adolescents (Zanoni & Mayer, 2014), or 7–53% in sub-Saharan Africa (Sutcliffe, et al., 2008), pointing to the critical importance of development and dissemination of interventions to improve clinic attendance and medication adherence in this population. Barriers to clinic attendance and medication adherence were similar to those identified in previous literature (Haberer & Mellins, 2009; Li et al., 2010; Ogbuji & Oke, 2010; Vreeman, Wiehe, Pearce, & Nyandiko, 2008). One unexpected barrier was the interplay of food insecurity with medication adherence. Because ARV medications often have to be taken with food, adolescents who have inconsistent access to food in the morning can miss the administration window waiting to locate food and thus miss their morning or evening dose. Another barrier was limited understanding of HIV, particularly around how the virus was acquired. Both of

these barriers suggest that youth would benefit from more time to discuss their illness with informed adults or peers to clarify misconceptions and form strategies for integrating HIV care into their daily lives. Unfortunately, in resource-limited settings access to the treatment team is often brief; moreover, youth rarely discuss their illness with the few caregivers who know about their diagnosis.

Peer support groups have been shown to be beneficial in providing a forum for discussion of living with HIV in a stigma free environment (Amzel et al., 2013). Such groups can help adolescents better address the strong emotions around their illness, provide models and ideas for handling day-to-day challenges of disease management, and provide a forum to learn skills such as how to when, how, and to whom to disclose their illness. Finding ways of integrating additional support from parents/caregivers, the medical team, and peers will likely help Ghanaian adolescents living with HIV to improve their disease management and quality of life.

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Table 1

Descriptive Statistics for Quantitative Measures

Mean (95% CI) or % (n)	Full Sample <i>n</i> = 40	Qualitative Subset <i>n</i> = 20
Physical Health		
Dermatological Symptoms	20% (8)	35% (7)
Other symptoms	13% (5)	10% (2)
Clinical Staging		
Stage 1	10% (4)	10% (2)
Stage 2	25% (10)	15% (3)
Stage 3	20% (8)	20% (4)
Stage 4	30% (12)	45% (9)
CD4 > 500	55% (21)	55% (11)
Virologic Suppressed	33% (13)	40% (8)
On 1 st line treatment	95% (38)	100% (20)
Concomitant Medications	75% (30)	20% (4)
Adherence		
Always	20% (8)	25% (5)
Often	5% (2)	5% (1)
Sometimes	45% (18)	45% (9)
Never	23% (9)	20% (4)
Psychological Well-Being		
WHO 5 WBI		
Total Score (scale: 0–100)	69.00 (60.02 to 77.98)	66.20 (54.42 to 77.99)
% who screened positive	52% (21)	55% (11)
ICD10 Depression		
Total Score (scale: 0–50)	10.80 (8.31 to 13.74)	14.26 (9.58 to 19.89)
% who screened positive (ICD-10)	3% (1)	0% (0)
% who reported at least mild depressive symptoms	10% (4)	21% (4)
Social Context		
Others' fear of contagion (scale: 1=Disagree;3 =Agree)	2.78 (2.62 to 2.94)	2.58 (2.27 to 2.89)
Others' negative judgment (scale: 1=Disagree;3 =Agree)	2.65 (2.50 to 2.81)	2.58 (2.33 to 2.82)
% Reporting Discrimination	13% (5)	25% (5)
Concern about accidental disclosure (scale: 1=Strongly Disagree;4 =Strongly Agree)	1.97 (1.81 to 2.12)	1.86 (1.54 to 2.19)
% reporting any emotional support	55% (22)	65% (13)
Social Activity (scale: 1=Much less than most;5=Much more than most)	2.42 (2.07 to 2.76)	2.15 (1.71 to 2.59)
Amount of financial support (scale: 1=Very Difficult : 5=Very Easy)	1.81 (1.45 to 2.17)	1.80 (1.31 to 2.29)
% reporting any tangible support	15% (6)	15% (3)
Quality of Life		
Physical Health (scale: 4 to 20)	13.42 (12.91 to 13.92)	13.09 (12.34 to 13.74)
Psychological Health (scale: 4 to 20)	11.54 (11.01 to 12.09)	11.58 (10.75 to 12.35)

Mean (95% CI) or % (n)	Full Sample <i>n</i> = 40	Qualitative Subset <i>n</i> = 20
Social Relationships (scale: 4 to 20)	12.94 (11.93 to 14.02)	13.07 (11.87 to 14.20)
Environment (scale: 4 to 20)	12.71 (11.87 to 13.50)	12.15 (11.00 to 13.18)

Table 2

Qualitative Themes

Categories&Themes	Examples
Physical Health	
General health behaviors	Eating healthy, drinking clean water, working hard, doing well in school
HIV knowledge	Understanding the need to take medication to stay healthy, limited understanding of how they contracted the illness
Barriers to HIV medication	Access to medication, access to food, forgetfulness, perceived or actual side effects, fear of unintended disclosure, conflict with day-to-day activities
Strategies to take medication	Reminders from families, tangible support from families (sharing of food or money), using phone as an alarm, using environmental cues as reminders, recognition of health benefits
Barriers to clinic attendance	Conflict with school schedule, avoidance of illness, not wanting to miss school for fear of stigma, transportation costs, forgetfulness
Strategies to attend clinic	Tangible support from family (rides or money), prepared explanations for why they have to attend the hospital, reminder calls from the clinic
Psychological Well-Being	
Distress about life circumstances	Loss of family, food insecurity, access to education, poor treatment by family or friends.
Distress about HIV	Worry about of the future, sadness when thinking about HIV, social comparisons, perceived stigma
Coping strategies for HIV	Avoidance of reminders, religious faith, distraction, empowerment, withdraw from others, cognitive reframing, hope for the future, support from family and friends, lack of opportunity to discuss HIV with others
Social Context	
Social Support	Tangible support, Sense of belonging or relational support, Informational support, emotional support, medication reminders, help with travel to clinic appointments
Disclosure	Limiting the number of people who know about status, desire to expand circle of support contrasted with fear of stigma
Stigma	Concern about how others will treat participant if they learn about HIV diagnosis, some evidence of discrimination by family and teasing about height and short stature, Being compared to family and friends because of small stature, skin lesions, or being "sickly"
Quality of Life	
Quality of Life Enhancement	Engaging in enjoyable activities, finding a sense of purpose, sense of social responsibility, strong focus on education
Barriers to Quality of Life	Limited resources, difficulties with family, poor health, HIV management
Intervention	
What others can do to help with HIV	Provide financial assistance for medication and transportation, support group to openly talk about HIV, help with transportation to clinic, improve food insecurity, provide opportunity to talk to people about HIV
What they hope to gain	Chances to ask questions, learn more about HIV, receive encouragement from staff, make friends with adolescents who understand what they are experiencing
Challenges to attending a group	Concern about unintended disclosure, transportation, lack of parental consent (typically related to parental fear of disclosure), stigma of frequent visits to the hospital clinic