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Caregiver mental health and HIV-infected child wellness: perspectives from Ugandan caregivers

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Abstract

Prior studies indicate a substantial link between maternal depression and early child health but give limited consideration to the direction of this relationship or the context in which it occurs. We sought to create a contextually informed conceptual framework of this relationship through semi-structured interviews with women that had lived experience of caring for an HIV-infected child while coping with depression and anxiety symptoms. Caregivers explained their role in raising healthy children as complex and complicated by poverty, stigma, and isolation. Caregivers discussed the effects of their own mental health on child well-being as primarily emotional and behavioral, and explained how looking after a child could bring distress, particularly when unable to provide desired care for sick children. Our findings suggest the need for investigation of the

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reciprocal effects of child sickness on caregiver wellness and for integrated programs that holistically address the needs of HIV-affected families.

Keywords

HIV; mental health; child health; Uganda; qualitative

Background

Maternal depression and anxiety are associated with poor child socioemotional, cognitive, and physical development (Kingston, McDonald, Austin, & Tough, 2015; Murray & Cooper, 1997; Surkan, Kennedy, Hurley, & Black, 2011). While children of depressed mothers are estimated to have twice the odds of stunting and wasting, the cross-sectional design of most studies on this topic has led to a call for future research on how poor child growth and health may negatively impact caregiver mental health (Surkan et al., 2011). Further, studies that have assessed the reciprocal effect of child illness on maternal mental health have largely been limited to English-speaking high-resource country populations (Shudy et al., 2006).

Understanding the relationship between caregiver distress and HIV-infected child health is critical as these children are at particular risk for poor growth (Isanaka, Duggan, & Fawzi, 2009). Many women caring for children living with HIV may also be HIV-positive, and a substantial proportion of women living with HIV/AIDS experience depression and anxiety (Breuer, Myer, Struthers, & Joska, 2011; Kapetanovic, Dass-Brailsford, Nora, & Talisman, 2014). Parenting-related burden and stress are potential contributors to distress among individuals caring for HIV-infected children. Living with HIV/AIDS was associated with anxiety among South African caregivers, but these odds were compounded by caring for an HIV/AIDS orphan (Kuo, Cluver, Casale, & Lane, 2014). Parenting stress has also been found to predict poor mental health in caregivers of children with chronic illness (Cousino & Hazen, 2013), and to be associated with depression in US-based mothers living with HIV (Semple et al., 1997). Alternatively, feeling responsible for children facilitated coping among Ugandan women living with HIV (Medley, Kennedy, Lunyolo, & Sweat, 2009).

Research demonstrating heightened economic impacts of illness (Tekola, Reniers, Haile Mariam, Araya, & Davey, 2008), the importance of stigma (Kuo et al., 2014), and a differential relationship of social support to mental health (Casale, Wild, Cluver, & Kuo, 2015) among adults living with HIV points to the importance of contextual factors when examining caregiver distress and HIV-infected child health. For example, social support buffered the effect of living with a chronic illness on depression in women caring for children in HIV-endemic South African communities, but not if that illness was HIV/AIDS (Casale et al., 2015). Using a qualitative approach to elicit caregivers' perspectives, we sought to create a contextually embedded conceptual framework of the relationship between caregiver mental health and HIV-infected child well-being that could inform support services for families living with HIV.

Methods

Participants and eligibility

Study participants were caregivers of young HIV-infected children enrolled in the control arm of a randomized controlled trial (RCT) of a parenting intervention. Control women received 12 months of biweekly training on nutrition, hygiene, and HIV, as well as a nutritional supplement. RCT recruitment occurred between March 2012 and November 2013 through local clinics and non-governmental organizations providing HIV care in Tororo and Busia district in eastern Uganda. Tororo is predominantly rural, has a high malaria incidence, and approximately a quarter of its population lives below the poverty line (Sandison et al., 2011; Uganda Bureau of Statistics and ICF International Inc., 2012). Female caregivers were eligible if they had a child aged 2 to 5 that they cared for the majority of the time. Exclusion criteria were presence of a severe mental illness (e.g. psychosis) that would prevent engagement in training or required immediate intervention (e.g. a plan to commit suicide).

Of the 60 caregivers of HIV-infected children in the control arm, we purposefully sampled nine based on Hopkins Symptom Checklist for Depression and Anxiety (HSCL-25) responses (Hesbacher, Rickels, Morris, Newman, & Rosenfeld, 1980; Winokur, Winokur, Rickels, & Cox, 1984). As there is no validated cut-off for the HSCL-25 in this population, we selected women who scored above the sample mean as able to speak to the experience of raising a child while experiencing internalizing symptoms. To gain diverse perspectives, we also sought maximum variation on child health outcomes (i.e. caregivers with and without children classified as stunted, wasted, or underweight). Sampled women were nearing or at the end of a yearlong maintenance period following intervention completion and ranged from age 23 to 45 at study baseline. Seven were the study child's biological mother, eight were HIV-positive, and six were married. Four staff members were also interviewed; staff inclusion criteria were having provided the control program to HIV-infected women in the trial.

Procedures

Global Health Uganda (GHU; the local implementing partner) contacted women to assess interest in participating. With permission, interviewers met women to discuss the study and conduct oral informed consent. Caregivers chose a private location for their interviews, typically their homes; staff interviews occurred at GHU's office. Using an open-ended guide, we conducted 20 semi-structured in-depth interviews (IDIs) with caregivers and staff over three-weeks in August 2014. The guide covered contributors to poor child health, qualities of caregivers of healthy children, experiences with child illness, and how problems faced by caregivers affect children. Seven caregivers who were particularly informative agreed to be interviewed twice to allow for iteration and further exploration of concepts. Four university-educated Ugandans were trained to conduct IDIs with caregivers in a local language (Jopadhola or Ateso). Study authors SM and IF led the two-day training, which included didactic components and role-plays; they then provided daily support and reviewed interviews. They also conducted staff interviews in English. Interviewers worked in pairs with one conducting the interview and taking notes while the other solely transcribed. The

two interviewers reviewed notes and produced a final transcript together. As only one interviewer was comfortable interviewing in Ateso, transcripts from two participants were based on one interviewer's notes. The Michigan State Institutional Review Board and Makerere University's School of Medicine Research and Ethics Committee provided ethical approval. Names included below are pseudonyms.

Data analysis

The analysis process began with line-by-line coding of all caregiver and staff transcripts to develop emergent themes using Nvivo software (*QSR International Pty Ltd*, 2014). All transcripts were then reviewed with a questionnaire that contained codes for emergent and two *a priori* themes (effects of caregiver mental health on child well-being and the reciprocal). To provide additional context, two case study narratives were developed by reviewing transcripts and quantitative data provided in the RCT. Cases were chosen to be paradigmatic of developed themes and portray diverse experiences. The analysis was conducted by SM and IF and OC reviewed results to enhance confirmability.

Results

The resulting conceptual framework is detailed in Figure 1. Below we explore caregivers' role in raising a healthy child ("you have to struggle to provide") and then detail the pathways caregivers described between their mental health and their children's health. This includes the overall effect of caregiver health on child well-being ("they also suffer") and the overall impact of child ill health on caregivers' lives ("it is like you are the one who is sick"). In addition, we highlight a potential mechanism of the interrelationship: an inability to adequately care for a child, in part due to poverty, and how it can affect caregiver mental health and wellness ("asking yourself many questions without answers"). We also discuss the role of social support in this process ("I'm just alone as you see me").

"You have to struggle to survive:" Fulfilling the caregiving role

Women described multiple caregiving practices as essential to children's health: maintaining cleanliness, encouraging play, limiting work, teaching, listening, and making children feel loved. The duty most discussed in relation to growth was providing a sufficient, varied diet. Caregivers most commonly described poverty, exacerbated by their own illness, as limiting their ability to meet parenting demands:

When I was not sick, I could dig and have much food in all seasons that I could eat and even give out some food to other people like the neighbors. I could work and get some money that could really help me with my children.... But now that I'm sick, with the drugs I'm taking, sometimes it makes me weak and I can't do all this work. The child can also be worried because he will know that 'my parent is sick,' and the child will not feel well.

-Agnes

“They also suffer:” How caregivers’ mental health affects children

As Agnes’ described, children were said to notice and be affected by caregiver sickness and distress. Failures to provide were said to make children “think a lot” or “feel abandoned.” Women explained that stressed caregivers might engage in harmful practices like shouting. One trainer echoed this, saying caregivers could become aggressive or withdrawn when depressed, affecting the child’s health:

When they are depressed, they don’t want to be with the child playing. They mostly want to be alone or doing something... Even the feeding, the nutrition that we train them on, if the mother is depressed she will not remember to cook. Food will not be ready, because she was sitting around alone.

Further, multiple caregivers expressed that children exhibited the same symptoms (e.g. sadness) and behaviors (e.g. refusal to eat) in response to a caregiver being unwell.

“When the child is sick, it’s like you are the one who is sick:” How child sickness affects caregivers’ lives

Child sickness placed additional burden on the caregiver and depleted household resources. Caring for a sick child was described as a complicated process that included taking children to multiple providers, procuring and appropriately administering medicine or home remedies, and continually monitoring. Mary explains that with a sick child:

You think a lot, for instance if you have even lost one to death, you think this one will also die. This just makes your brain confused, like you want to run mad. You are not settled in one place, you move from one place to another looking for how to treat your child... You see you get confused and sometimes you even do not have money so you have to look for money around.

Caregivers struggled to afford medicine, transport to care, and to stay with a child admitted to the clinic; to manage, some borrowed money or sold off crops. Seeking care kept women from earning money and growing food, as “*ogoye gima katho malo*” (nothing can continue) when a child is sick. Caregivers had to navigate these challenges while dealing with the stress and emotion associated with seeing their child ill, such as crying, *kumo* (sorrow), pain in the heart, and most predominantly, worry or *ka paro teki teki* (over thinking). With an ill child:

You start thinking a lot, and this makes you want to be sick and you don’t even know whether the child will survive. It gives me pressure. It brings pressure because it brings a lot of thoughts in my head. It makes my heart beat a lot, even if I’m fine myself, the temperature is raising and eventually I can feel sick.

-Ethel

“Asking yourself many questions without answers:” Mental health and the inability to provide

These quotes highlight that an inability to perform caregiving duties induced distress. When asked how child sickness affected her life, Mary explained:

You may need to take the child to the hospital and yet you do not have any money. That is when thoughts come your way... If you have many thoughts, your life cannot be fine. You even move while absent minded and you can even develop ulcers if you take days without eating you can also fall sick. For us who are HIV-positive, if you have many thoughts your *askari* (white blood cells) reduce and you may die quickly.

This stress was not only limited to times of emergencies or sickness.

I feel sad because of many thoughts. These thoughts come when school time reaches and I start thinking of where to get money because my children are very bright that leaving them to stay at home is not good. I will be wasting them if I left them at home.

-*Esther*

Ultimately, caregivers described a cycle in which child sickness and caregiver distress interacted to exacerbate poverty. In the face of many barriers, some caregivers came to feel they could not change their situation.

Case study 1: Ethel

Ethel is a mother in her early 20s, living with HIV and caring for multiple children. Her little girl, Alowo, was 2 years old when they enrolled in the parent RCT together. Previously widowed, Ethel found a new partner who also passed away. Describing herself as both mother and father to her children, Ethel worked to grow food on her own but has difficulty getting a good yield of crops on her small parcel of land. At times, the family would not have enough food. Refusing to steal from others, on these days the family would go to sleep hungry.

Alowo repeatedly got sick with malaria during the study. Alowo's fever would come on quickly and Ethel would worry whether or not she would survive. Ethel described having no money at times to buy medicine or take her to a private clinic, so she would take her to the hospital where treatment was free. However, not every drug was always available there and transportation was a challenge. Ethel described once having to beg a neighbor to allow her to borrow a bicycle just to get Alowo there. She struggled to get Alowo to eat when sick. During these times, Alowo would ask for "good food" like meat and rice that Ethel couldn't afford now that her husband was gone. The hospital would tell her too that the child needed to eat better, but Ethel felt at a loss for how to make this possible. Though the brother of her late husband lived nearby, he would not help in situations where they did not have enough food, when he would hear children were sick, or when he would see the poor condition of their house. Her own relatives were either too old to help or themselves were struggling to provide for their own families.

Ethel experienced a high level of depression and anxiety symptoms at the beginning of the study that lessened, but again returned. In particular, Ethel reported having pain in her heart, many thoughts, and feeling fearful, sad, tense, and like everything was hard. She described that her children being sick and her struggle to try to care for them with limited resources would make her feel helpless and bring on some of these symptoms like having

too many thoughts. In addition, she had physical symptoms such as feeling low in energy or faint as well as experiencing a racing heart, poor appetite, and headaches. She described that when she would be plagued by many thoughts, she could feel herself grow sick, even feverish. Being sick and at times bedridden made it even harder for her to dig to provide food for her children. She felt when she was sick her children would worry and wonder if she too might die.

Despite all these challenges, Ethel is resourceful and would try many different coping strategies to deal with her situation. She used work sometimes to distract herself from the difficult things in life or turned to prayer or religious scripture. She shared her feelings or problems with friends, like when her child was sick. They would give her support and encourage her to be strong for her children. Indeed, Ethel felt she understood her children's needs and as their mother worked very hard to make sure they had food and treatment when ill despite an incredibly difficult situation, dedicating all her time to them. Ultimately, though Alowo was stunted and severely underweight early on, she caught up in growth over time and was not malnourished at the end of the study. She also started on ARVs and Ethel said after this her health generally improved.

“I’m just alone as you see me:” The duality of support and isolation

Trainers felt it was critical for women to have supportive families. Caregivers described instances when families provided instrumental support by giving money, food, or even temporarily housing children. Neighbors, friends, the church, and local NGOs were also important sources of assistance and emotional support. However, many participants felt isolated and alone as caregivers, even when receiving tangible support from others. Accordingly, both women and trainers explained that family could be a source of conflict and stigma, even if some members were supportive. Verbal abuse of women known to be HIV-positive, particularly widows, was reported. Child misbehavior, understood as in part due to failures to provide, also disrupted networks and caused quarrels within and between households.

Case study 2: Mary

Mary was a widow in her 30s living with HIV when she and her child (Moses) began participating in the parent RCT. As the only adult in her household, she also cared for two other children while still living in her former husband's community. The family was poor relative to others in the study and had no cows or goats to supplement their income. Their situation did improve some over time; for instance, she was eventually able to get iron sheets to replace her thatch roof.

Moses began taking ARVs when he was 2 years old. Mary described always giving him his medicine twice a day, though she was concerned that she sometimes could not provide Moses with the food he wanted when taking his medicine. Throughout the study, Moses had an undetectable viral load. His growth was normal for his age, which Mary noticed to be the case ever since he began taking his medicine. However, Mary did describe that he would intermittently develop fever, especially during times when the family did not have enough good food to eat. She would use cool clothes and make home

remedies that her trainer taught her to help Moses during these times. When he would not improve, she borrowed money when necessary to take him to the local health center. She even had a nurse's number there whom she could call to help get advice or medicine. Once during the study Moses had to be hospitalized for severe malaria. Mary described the doctor as being unhappy with her because the child was near death, though Moses thankfully recovered.

Mary experienced intermittent symptoms of depression and anxiety throughout her time in the study. In particular, she often began to cry easily, was worried with many thoughts, and felt hopeless, lonely, or like everything in life was hard. At times these symptoms were very severe. Though she reported being able to function well in her daily life, she did sometimes lose her appetite and have difficulty sleeping. She said when she felt like this her children would feel bad too, worrying about her and knowing things would be different if their father was alive. It could even bring them to not eat. She described the source of her troubling thoughts as worrying about her children when they were sick and how she would provide them care without money, but also worrying about how she would provide for their other needs like school fees. In addition, she said sometimes others would abuse her for taking medicine or she would quarrel with her inlaws. During these quarrels, Mary said that they would tell her terrible things like that she was responsible for her husband's death. Mary described that talking to people like her friends helped her during these sad times. She also commonly used her religion as a source of support, engaging in prayer or drawing on scripture.

Despite the distress some family members could cause her, Mary also discussed that family could be a source of both financial and emotional support. Her brother purchased a cell phone for her that she could use to call him when the child was sick and then he would help take the child to the hospital. Her mom would bring food to sick children and both would keep the child during holidays. Her brother who had income from selling extra crops would buy clothes and both would play with and care for the child, though Mary emphasized that no one could care for a child as well as a mother. Overall, Mary's story illustrates the resilience of caregivers and children affected by HIV and how family can be a source of both stigma and strength.

Discussion

The conceptual framework of caregiver mental health and child wellness we developed based on caregivers' perspectives differs in important ways from the unidirectional relationship commonly assessed in quantitative studies. Though caregivers understood their emotions and behaviors to impact their children, they also discussed the multifaceted effects of child sickness on their mental health, resources, and ability to earn money. As shown in the case studies, women worked hard to provide and care for their children despite challenges posed by illness and death in the family. This struggle of trying, and at times failing, to meet the complex demands of parenthood was exacerbated by poverty (as in Ethel's case) and linked to caregiver illness and distress.

This framework points to the importance of parenting-related stress in understanding caregivers' mental health. In South Africa, 40% of caregivers of AIDS orphans indicated a high level of caregiving burden, including feelings of stress, anger, and inadequacy as a provider (Kidman & Thurman, 2014). Important predictors of this burden were low income, food insecurity, and caregiver AIDS-related illness. The financial strain of child illness could be an additional predictor of parenting stress for caregivers of HIV-infected children, who are at risk of a wide range of morbidities. The financial impact of child sickness on households that participants referenced has been quantitatively demonstrated in Bangladesh, where 75% of families of children hospitalized for pneumonia reported compensatory borrowing or selling of possessions. Further, approximately half reported reductions in food and education spending (Alamgir, Naheed, & Luby, 2010).

Parenting stress may also arise in association with *therapeutic citizenship*, a social contract generated between individuals living with HIV/AIDS and treatment providers (Nguyen, Ako, Niamba, Sylla, & Tiendrébéogo, 2007). Just as national citizenship entails individuals undertaking certain responsibilities to the state in exchange for benefits, people living with HIV/AIDS assume responsibilities through engagement in treatment. For instance, a study in central Uganda found that interactions with HIV/AIDS support organizations inculcated individuals with a sense of responsibility for the promotion of their health and that of others, which incorporated ideas about the importance of nutrition and hygiene (Russell, Namukwaya, Zalwango, & Seeley, 2015). This type of responsibility was clearly articulated by caregivers in our study in relation to caring for their children. Our study suggests that in the context of poverty, a potential negative ramification of viewing the assurance of children's health as a moral obligation is the sense of distress caregivers experience when unable to fulfill this role.

As discussed by caregivers in this study, hunger has emerged as a major concern among sub-Saharan African populations living with HIV. ARVs have enabled individuals to continue to live with HIV, but may simultaneously encourage patients' appetites while doing nothing to eliminate the daily struggle to fulfill basic needs (Kalofonos, 2010). The complement to the duty caregivers may assume through therapeutic citizenship is the generation of expectations for services beyond ART provision that address these broader socioeconomic problems. Our findings regarding the saliency of scarcity and distress point specifically to the importance of income generation opportunities, food support, and mental health services for caregivers of HIV-infected children. Accordingly, there is a great need for investigation into effective and scalable psychosocial programming that could be incorporated into HIV/AIDS services, as well as capacity building in these areas.

It is important to note several positive aspects of caregivers' narratives. Ethel's case demonstrates how children can thrive despite environmental risks, while Mary's shows the instrumental and emotional support family can provide. Thurman, Jarabi, & Rice (2012) found that while support group participation did not predict mental health, there were benefits for HIV-affected women and their children. While promotion of social support may be a promising strategy for bolstering caregivers' psychosocial health, Mary's story also demonstrates a need for multi-pronged advocacy aimed at reducing stigma.

Limitations

Due to their busy lives, participants were often tired or interrupted. We dealt with this challenge by keeping interviews under an hour and rescheduling as necessary. Although interviewers were not GHU employees and we emphasized that interviews would not affect RCT participation or trainers' jobs, participants may have filtered what they shared to avoid affecting their relationship with the RCT team. While using interviewer notes for transcripts was faster than transcribing recordings in this context, providing an opportunity for iteration, transcripts may have been incomplete. We tried to minimize this possibility by interviewing in pairs. As women with psychosis were excluded, these findings only speak to women's perspectives on symptoms of common mental health problems. As a qualitative study, depth of understanding from individuals with lived experience was sought, not representativeness; our findings can however guide future quantitative research that has potential to be generalizable. Study strengths include triangulation of sources, incorporation of quantitative data, and iteration over multiple interviews.

Conclusions

Caregivers described a complicated, bidirectional relationship between their well-being and that of their children. The reciprocal impact of child sickness on caregivers' mental health and household economics warrants further investigation. In particular, inability to perform caregiver duties due to poverty, functional impairment, and isolation should be assessed as mediators. Our findings also suggest that pediatric HIV care should include livelihood or food support, caregiver mental health screening, and be embedded within a broader movement to reduce HIV/AIDS stigma.

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Figure 1.
Conceptual framework of the relationship between caregiver mental health and child well-being as described by caregivers.