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Correlates of Depression among Caregivers of Children Affected by HIV/AIDS in Uganda: Findings from the Suubi-Maka Family Study

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Abstract

This study uses the baseline (wave 1) data from a 4-year (2008-2012) longitudinal study called the Suubi-Maka family economic empowerment intervention for AIDS-orphaned children in Uganda funded by the National Institute of Mental Health (Grant # RMH081763A). Specifically, using baseline data from the Suubi-Maka study, this paper provides a contextualized understanding of depression levels among caregivers for AIDS-orphaned children in two rural communities heavily affected by AIDS in Uganda: Rakai and Masaka districts. Using baseline data collected from caregivers of children orphaned by AIDS (N=297) the study examines the factors that influence reported depression levels of caregivers of AIDS-orphaned children in rural communities of Uganda. We specifically use OLS regression methods. In the analysis we control for several demographic factors, including age, gender, assets, social support, and caregiving status. We find that caregivers' reported economic status and social support system are highly correlated with caregivers' reported depression scores. Specifically, caregivers with cash savings and a strong family support system reported better depression scores. These findings have implications for community development practice and programming. Specifically, the study highlights a need for family economic empowerment programs and, strengthened family support among caregivers for AIDS-orphaned children, especially those caregivers with reported poor mental health functioning.

Keywords

Depression; mental health; HIV/AIDS; care giving; orphans; Uganda

Although the prevalence of HIV/AIDS is on the decline in Sub-Saharan Africa, the number of children affected by the disease continues to increase. Close to 16.6 million children have been orphaned by HIV/AIDS within the Sub-Saharan region (UNAIDS, 2010). In Uganda approximately 1.2 million children (45% of all orphans) have been orphaned by HIV/AIDS. Although some orphaned children have been placed in institutions or orphanages, uptake has been more evident in the integration of children into communities with their (the orphaned

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children) extended families (Kuo & Operario, 2009). Data collected in the 1999-2000 household survey found that 25% of all Ugandan families provided care to children whose parents have either died from HIV/AIDS or are unable to provide adequate care due to complications of the disease (Uganda Ministry of Gender Labour and Social Development, 2004). Caregivers of these children report facing added stressors including financial and emotional strains brought about by the added familial responsibilities (Jacob, Smith, Hite, & Cheng, 2004; Kagotho, 2011). These stressors adversely affect the caregiver-child relationship. Using data from the Suubi-Maka family economic empowerment program, this study investigates the reported depressive symptoms of individuals providing care to children affected by AIDS in two communities in Uganda heavily affected by HIV/AIDS: Rakai and Masaka Districts. Modeled after the individual development accounts (IDAs), the Suubi-Maka combines matched savings accounts and health promotion strategies to empower families impacted by HIV/AIDS. This study addresses two research questions: 1) to what extent do caregivers of AIDS-orphaned children report depression symptoms? 2) what are the correlates of depression among caregivers of AIDS-orphaned children? These two questions are important because the community-level infrastructure developed in economic empowerment programs for families affected by HIV/AIDS have been identified as an integral gateway in the delivery of mental health services (Prince, Harwood, Thomas, & Mann, 1998).

Changing Family Configurations

Uganda has one of the highest HIV prevalence rates in sub-Saharan Africa. Concerted government and non-governmental intervention efforts have led to a dramatic decline in national prevalence which currently stand at approximately 5% (UNAIDS/WHO, 2008). These impressive declines notwithstanding, the number of children who have been orphaned by the disease continues to rise. One of the ways through which communities have responded to this need has been the reconfiguring of the nuclear family. National statistics indicate that one in every four families in Uganda provides care to children orphaned by HIV/AIDS (Uganda Ministry of Gender Labour and Social Development, 2004, 2006). These changing family structures do exert a financial strain on households and communities already struggling to cope (Ssengonzi, 2007; UNICEF, 2006).

Care Giving and Mental Health

Globally, mental health disorders are more prevalent than initially thought. Approximately 10% of the entire global population suffers from a mental health disorder while one in every four families have at least one member with a diagnosable mental or behavioral health disorder (WHO, 2001). The association between HIV/AIDS and mental health is an especially salient area of study. The physiological and psychological effects of the disease, the effect of antiretroviral therapies, social stressors (including stigma and discrimination), and financial strains associated with the disease all inform the mental health status of individuals and families living with the disease. Identifying and addressing the mental health concerns of caregivers not only allows us to design community-level programs that would stop the condition from becoming chronic but also address individual health in these communities. The mental health status of parents is highly associated with child rearing practices and child well-being (Lyons-Ruth, Wolfe, & Lyubchik, 2000). Research on the mother-child relationship for instance has found that depressed mothers are more likely to physically and emotionally abuse and neglect their children. Scant research available on the paternal-child relationship also points to similar results with poor mental health associated with negative parenting practices (Bronte-Tinkew, Moore, Matthews, & Carrano, 2007; Francis & Wolfe, 2008).

Poverty and Depression

Poverty both at the community (macro) and individual (micro) levels is associated with poor mental health functioning with low income countries and economically disenfranchised communities in higher income countries bearing a large health burden as a result of neuro-psychiatric disorders (WHO, 2001). The accumulation of assets, including financial savings (M. S. Sherraden, Moore Mc Bride, & Beverly, 2010), and micro-enterprises projects (Mohindra, Haddad, & Narayana, 2008) have been associated with better mental health outcomes. (For an explicit connection between asset-accumulation and mental health functioning, see (Ssewamala, Han, Neilands, Ismayilova, & Sperber, 2010)). Sherraden (1991) argues that this can be explained by assets' ability to influence an individual's perception of future possibilities. The potential and the ability to leverage assets towards future utilization is likely to reduce stress associated with navigating future obstacles.

Social support is a feature in many income and asset generating programs. Defined as the support individual access through their relationships it has been a fixture in the group-based micro-enterprise model (Mayoux, 2001). As caregivers who are socially isolated, and lack support from family and friends are more likely to show symptoms of depression (Musil, 1998), social support becomes a necessary component in interventions targeted towards these individuals. Family economic empowerment programs in poor sub-Saharan communities, such as Suubi-Maka program, have integrated peer and mentorship groups where participants get together to share their experiences in the program including saving mechanisms and parenting tips.

Methods

Data for this study was drawn from the first wave of the Suubi-Maka family economic empowerment program, currently being implemented in Rakai and Masaka districts, located in Southern Uganda. The Suubi-Maka program (2008-2012) funded by the National Institute of Mental Health (Grant # RMH081763A) implements and evaluates the impacts of a family economic empowerment intervention among families providing care to children orphaned by HIV/AIDS. AIDS-orphaned children in the study are defined as any child who has lost one or both biological parents to AIDS. Hence, participants included both single and double-orphans.

The Suubi-Maka intervention program combines matched savings accounts and health-promotion strategies to empower families caring for children orphaned by AIDS within communities. A foundational premise of the program is to strengthen the functioning of families so orphaned children would be cared for within their communities, and within a family environment (as much as possible), instead of, for example, being placed in institutional care, whose short-comings to the overall psychosocial functioning and mental wellbeing of children have been well documented (Maclean, 2003; Nelson III et al., 2007; Ssewamala & Ismayilova, 2009). Using an experimental design the program has enrolled AIDS-orphaned children and their caregivers from 10 rural public primary schools in Rakai and Masaka, two districts heavily affected by HIV/AIDS.

Specifically, this paper used data collected at wave 1 (baseline). As a family-focused study Suubi-Maka recruited and interviewed both the child and the child's primary caregiver (as dyads). Each dyad (child and caregiver/parent) was consented separately and interviewed separately. This study specifically reports findings from the parents/caregivers. Each respondent participated in a 90-minute survey administered by trained Ugandan research assistants in either English or Luganda (the native language).

Measures were adapted from (Bhana et al., 2004; Ssewamala, Alicea, Bannon, & Ismayilova, 2008; Tolan, Hanish, McKay, & Dickey, 2002) and have been previously used in Africa (and/or populations of African descent) with excellent psychometric properties (Bhana, et al., 2004). Specifically, the outcome depression variable was a composite of questions adapted from Bhana et al., 2004 and Ssewamala et al., 2008. Each respondent's likert scale responses were totaled creating a continuous variable with a higher score denoting higher depression symptoms. The scale demonstrated good internal consistency (Chronbach's alpha = .77). Caregivers were asked to rate their emotional experiences including "*being easily annoyed or irritated, feeling lonely even when with other people, poor appetite, trouble falling asleep, and feeling inferior to others*".

Age, gender, assets, social support (both financial and familial), and care giving status were included in the model as independent variables. The age of a caregiver is associated with both mental and physical health outcomes. Age as a control variable is especially important in the sub-Saharan context where the impact of HIV/AIDS has led to households headed by older adults (such as grandparents) and adolescents and young-adults (including siblings). In regards to gender, women, in general, have been found to have greater preponderance to depression as compared to men. The data contained two main asset variables, physical assets (including a home, garden, farm animals, businesses, cars, and bicycles) and cash savings. Analysis of the data however indicated that with the exception of seven families all reported having at least one physical asset. Therefore due to the lack of variability in the physical assets variable we elected to use cash savings as a measure of family assets. We used two variables to measure social support, financial support and family support. Financial support was a self-report dichotomous variable indicating the presence of external financial assistance flowing into the household. Social support, a count variable was constructed from a series of question measuring family cohesion and support. Questions used in the creation of the family support variable explored the cohesion, and reciprocity of the family relationship by asking caregivers to rate the amount of time their families spent together, how often they sought help from each other, listened to each other, and did things together as a family unit. Two variables were used to measure the construct of care-giving. The first was a variable denoting the orphan status of the child (single orphan =1, double orphan =0). It was hypothesized that providing care to a double orphan may be more stress inducing as compared to providing care for single orphans where one parent may still be available to provide financial and emotional support. The second care giving variable was created from a series of variables querying the presence of any HIV positive household member.

Pearson correlation and chi-squares were employed to determine variable associations. A multiple regression model was constructed to compute the effects of assets and social support in determining depression among caregivers after controlling for demographic variables. Standardized betas were compared to determine the varying strengths of each variables contribution to the model. Variance inflation factors were examined to detect variable multicollinearity.

Results

Depression was scored on a scale of 0 to 44 (M= 13.4, SD= 8.04). Investigation on the high standard deviation identified four outliers (range 38-44) and as their characteristics did not significantly differ from those of other respondents they were not omitted from the analysis. The sample consisted of 297 caregivers with a mean age of 46 years (range 18-87 years). Approximately eighty percent of the sample was women. This is consistent with other studies on caregivers of orphaned children in Africa. Women were more likely to report higher depressive symptoms when compared to men ($t(294) = 2.6; p = 0.009$). Thirty five percent of the respondents had household savings with median savings reported at Uganda

Shillings 100,000 (equivalent to USD 50). Household savings ranged from Uganda Shillings 10,000 to 4,000,000 (USD 5 to 2000). Caregivers who reported having no savings had higher rates of depression symptoms ($t(295) = 2.66$; $p=0.008$). Family support was scored on a scale of 9 to 24. On average respondents indicated high levels of family support ($M=19.9$, $SD=3.6$). Pearson correlation indicated a statistically significant association between family support and depression ($r= -0.16$; $p=0.006$). Fifty eight percent were solely responsible for their household financial provision. Those who reported being the sole financial provider in the household reported lower depression symptoms ($t(295)=-2.58$; $p=0.0104$).

The variables (age, gender, assets, social support (both financial and familial), and care giving status) explained 8.6% of the OLS regression model ($F(290) 3.82$; $p=0.0006$). Savings, financial, and family social support were significant predictors in the model with financial support showing the larger effect on the dependent variable. Controlling for all other variables in the model a one unit increase in financial support resulted in a 0.149 standard deviation decrease in depression ($t=2.45$; $p=0.015$). Those who were solely responsible for their household finances were less likely to report depression. Respondents who reported higher levels of family support were less likely to report high levels of depression symptoms. Holding all other variables constant one standard deviation increase in family support resulted in a 0.145 standard deviation decrease in depression ($t=-2.48$; $p=0.014$). Finally, one standard deviation increase in savings resulted in a 0.131 standard deviation decrease in caregiver depression ($t=-2.21$; $p=0.028$).

Discussion

In examining the correlates of self-reported depressive symptoms this study provides a contextualized understanding of mental health in low-income communities affected by HIV/AIDS. Specifically, in this section, we provide details on ways via which family economic programs, such as Suubi-Maka, would be used to address the community-level programming and policy responses to depression among caregivers of children affected by AIDS. Approximately eighty percent of all orphan caregivers in the study were female, who were also more likely to report higher levels of depression as compared to their male counterparts. Often encumbered with a multiplicity of roles such as parenting, care giving, and employment, women are more likely to experience mental and physical health strains (WHO, 2001). Women's vulnerability to depression was further aggravated by higher social isolation. Additional analysis did indicate that women reported lower levels of social support as compared to men. The question then becomes why are female caregivers so socially isolated? One reason could be that women providing care to family members impacted by HIV/AIDS could be more susceptible to stigma and the discrimination associated with the disease, which creates a gap or deficiency in their social support; and second, women who are caring for orphaned children may not be socializing –hence not taking advantage of their would-be community support –which reduces their social networks simply because of the demands of taking care of and/or caring for big families.

The family and financial support results offer a significant insight into the role of actual and perceived social support in life outcomes. Respondents with a weak support system reported higher rates of depression symptoms. Conversely, respondents who received assistance in meeting their household financial obligations exhibited higher depression symptoms. These seemingly contradictory results speak to the complex nature of the social support construct. How one perceives and interacts with their social support structure informs responses to their life situations. For example the belief that one's social network is dependable could buffer them against life stresses. Individuals who perceive their social networks as reliable would be more likely to view their life situation as less stressful and to develop better coping

mechanisms. This could explain why individuals not receiving external household funding have better mental health outcomes. Individuals who access social support are more likely to demonstrate poorer mental health such as depression. To determine whether that group of participants' depression emanated from lack of employment we investigated the employment status of each respondent. Approximately 83% of those receiving external assistance did indicate that they were also providing some form of financial support towards their household's upkeep. In addition only 29 participants (9.76%) self-identified as unemployed. However since there was no information on the percentage of their contribution towards household finances questions still linger.

Implications

The effects of family economic programs in Sub-Saharan Africa such as Suubi-Maka are an emerging section of the knowledge. The policy implications of these programs on families, households and individual economic well-being have been discussed elsewhere (Ssewamala, et al., 2010; Ssewamala & Ismayilova, 2009). The results from these data extend the discussion on the effects of family economic empowerment programs to focus on the implication on community mental health.

As policy makers and community development practitioners prepare to extend mental health services and information into previously underserved communities, working alongside interventions that have pre-established relationships would be advantageous. The Ugandan ministry of health has undertaken a health promotion and education campaign to prevent illnesses that include mental disease (Ministry of Health, 2010), creating partnerships with programs that have established relationships with community-level gatekeepers would facilitate this process. Further establishing relationships with programs that have educational and outreach components integrated in their core methodology could be a key intervention strategy.

At the community-level, initiating family level support interventions to ameliorate the effects of stress could be considered. Family support programs increase family resiliency and help families develop coping mechanisms. Consideration should be given to ensure culturally appropriate interventions with sufficient flexibility to account for the various family and caregiving structures currently in existence in HIV impacted communities.

Limitations

Depression is attributed to an intersection of genetic, biological, environmental, and social factors. However, the aims of the Suubi-Maka intervention program allow only for the collection of data focusing on the social factors associated with depression. As all respondents enrolled in the Suubi-Maka family economic empowerment intervention provide care to AIDS orphaned children a comparative group of caregivers residing in non-HIV/AIDS impacted households was not available for analysis.

Conclusion

This study has documented how family economic empowerment interventions could be involved in improving community mental health outcomes. Suubi-Maka's HIV/AIDS component makes its significance as a community gateway to mental health more vital. Although the intervention is designed to run for several years, by this writing only one wave of data is available. Future studies will include a longitudinal component of the actual impact of the Suubi-Maka intervention on caregivers' depression levels. Nevertheless, even with the one wave of data collected thus far, it is important to note that programs such as the

Suubi-Maka are probably well positioned to act as a gateway for mental health outreach due to their extensive community outreach.

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Table 1

Descriptive Statistics N= 297

Variable	N	%		
Gender				
Male	61	20.6		
Female	235	79.4		
Orphan hood				
Single	212	72.35		
Double	81	27.65		
HIV Care giving				
Yes	36	12.1		
No/DK	261	87.9		
Savings				
Yes	104	35.0		
No	193	65.0		
Financial support from others				
Yes	126	42.4		
No	171	57.6		
Variable	Mean	SD	Range	
Depression	13.4	8.04	0-44	
Age	43.3	14.6	18-87	
Family support	19.9	3.6	9-24	

Table 2

Multiple Regression: Determinants of Caregiver Depression

Variable	Coef	Standardized b	T	95% Conf interval
Gender (Male)	-1.14	-0.06	-0.93	-3.55 -1.27
Age	0.05	0.09	1.55	-.014 -0.12
Orphan (Single Orphan)	1.07	0.06	1.00	-1.04 -3.18
HIV Care giving (Yes)	-.044	-0.02	-0.31	-3.23 -2.35
Savings (Yes)	-2.21	-0.13	-2.21*	-4.18 --0.24
Family support	-0.33	-0.14	-2.48*	-0.06 --0.07
Financial support from others (Yes)	2.44	0.15	2.45*	0.48– 4.39
Constant	16.73		5.10	10.2-23.19

model f (290) 3.82; p=0.0006 R² 0.086