

Child prosociality within HIV-affected contexts: The impact of carer ill-health and orphan status.

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Considerable attention has been provided to the potential adverse outcomes for youth in the context of HIV and AIDS. Using data from a large community-based study on the psychosocial well-being of youth affected by HIV and AIDS, this paper advances a strength-based, resiliency perspective that is centred on the construct of prosociality. Data was derived from the *Young Carers South Africa Project*, where a cross-sectional household survey was conducted with 2,477 child-carer pairs in an HIV endemic community in the province of KwaZulu-Natal, South Africa. Analysis in this paper focuses on a subset of 2,136 child-carer pairs. Perceptions of child prosociality were assessed using the Prosocial Scale of the *Strengths and Difficulties Questionnaire (SDQ)*. Both child and carer responses were obtained to provide insight into the functioning of carer-child dyads. Descriptive and inferential analysis was conducted to explore ratings of child prosociality across different relational contexts affected by HIV and involving care for orphaned youths. Dual-affected households, where carers are ill with opportunistic infections and youth are orphaned due to AIDS, yielded the highest discrepancies with carers reporting low child prosociality and children self-reporting high prosociality. Carer ill health appears to play a role in differentiating child prosociality across relational contexts. Further research is needed to explore child prosociality as a protective mechanism in high HIV-endemic communities.

Keywords: carer-child dyad; HIV and AIDS; orphan; prosocial behaviour; South Africa

Introduction

Results of the 2011 South African census indicate that 18.8% of children aged 0-17 years (n=3 374 971) have faced the death of one or both parents (Statistics South Africa, 2012). Orphaned youth have been regarded as a vulnerable population in need of care and protection. In particular, children orphaned due to AIDS are associated with psychosocial challenges and mental health risks, as compared to other orphaned and non-orphaned youth (Atwine et al., 2005; Cluver et al., 2007; Doku, 2010). However, the assumption that orphanhood is the primary factor impacting psychosocial adjustment of children in the context of AIDS has been critiqued (Govender et al., 2014; Richter and Desmond, 2008). The recent turn towards 'AIDS-affected' communities has highlighted multiple pathways of risk and the accumulation of risks due to orphan status and carer ill-health (Cluver et al., 2013; Doku, 2010, Govender et al., 2014; Sherr et al., 2014).

Carers of youth orphaned due to AIDS may face resource-strains and financial pressures that negatively impact their psychological and physical well-being (Kuo and Operario, 2009). For the child, parental illness may trigger emotional distress and loss of freedoms due to caring for an unwell loved one, as well as disruptions to education, isolation, potential exploitation by family, and stigmas associated with AIDS orphan status (Chi and Li, 2013; Harms et al; 2010; Sherr et al., 2014). However, parental ill health may also present mutual prosocial benefits for the carer-child dyad through greater emotional closeness and intimacy (Tompkin, 2007), with children ascribing experiential gains through opportunities to learn new skills, increased maturity, and pride in caring (Skovdal and Ogutu, 2009).

In this regard, prosociality is defined as concern for the well-being of others through "sharing, donating, caring, comforting, and helping" (Caprara et al., 2012,

p.1289). Recent work on prosociality has explored associations with resiliency in contexts of adversity (Griese and Buhs, 2014; Haroz et al., 2013), supporting a shift towards the ‘strengths and assets’ approach to well-being (Ungar, 2008). The paper draws on data from a large scale study of psychosocial adjustment to explore child and carer perceptions of child prosociality across HIV-affected contexts. It is hypothesised that children from HIV-affected households will be associated with less prosociality than those in non-affected households, while children facing orphanhood and carer ill health may experience relatively higher risk for clinical levels of prosociality.

Method

Participants and Procedure

The data presented was derived from the *Young Carers South Africa Project*, with a particular focus on the KwaZulu-Natal province where both child and carer data was collected. In the original study, a cross-sectional household survey was conducted with 2,477 child-carer pairs to explore the physical and mental health of children and their carers across peri-urban sites in the eThekweni Municipality (48% of the sample) and rural sites from the uMhlabuyalingana Municipality in Northern KwaZulu-Natal (52% of the sample). Site selection was based on HIV prevalence rates ($\geq 30\%$ HIV prevalence among antenatal clinic attendees) (Department of Health, 2008), provincial health deprivation indices (Noble et al., 2006), and geographical location based on Statistics South Africa (2003) data. Within research sites, stratified random sampling was conducted in accordance with census enumeration areas for the urban site and tribal authority boundaries for the rural site.

Interviewers approached each household within the sampling area to determine eligibility for participation. Child participants were required to be between 10-17 years

of age, while the matched primary carer¹ had to be over 18 years of age. Self-reported ill carers were prioritised to ensure a large enough subsample of ill carers. In households with more than one eligible carer, or more than one eligible child cared for, the carer-child pair was selected using random means like a coin toss. A household survey questionnaire was used to guide individual face-to-face interviews with carers and children respectively, with interviews ranging in duration from 40 to 60 minutes. Survey questionnaires were translated into the local language prior to entering the field and were administered by interviewers proficient in English and isiZulu.

Ethical Considerations

Ethical approval for the study was obtained from all partner universities and the South African Departments of Education, Health and Social Development. Approval was also granted by the relevant municipalities and community authorities in each site. Both carer and child participants provided informed consent and assent to participate. Reported refusal rates were low (less than 1 %). The appointed interviewers received sensitivity training for engaging with families and vulnerable children, while referrals to local service agencies were available in the event that additional psychosocial support was requested.

In accordance with UNAIDS (2010) definition of orphanhood as children below 18 years of age who have faced the death of one or both parents, child participants in this sample were classified as non-orphans; children orphaned due to AIDS; children orphaned due to other reasons like homicide, road accidents, other illness/injury, and those orphaned due to undefined circumstance. The category of youth orphaned due to undefined circumstance (n=341 cases) was excluded in this analysis, as it was unclear

¹ A primary carer may be a biological or foster parent. He/she assumes the main responsibility for addressing the economic and psychosocial welfare of the child.

whether this group included cases where carers had died via AIDS-related illnesses, thereby introducing a margin of error within the analysis. Thus data analyses focus on a sample of n=2136 matched child-carer pairs. Parental death due to AIDS was determined through respondent self-report, where offered, and the use of the verbal autopsy tool. The verbal autopsy is a questioning method employed in contexts of high HIV-prevalence (over 20%) to identify symptom characteristic of AIDS (World Health Organization, 2005) and has been validated in studies across sub-Saharan Africa (Hosegood et al., 2004).

Measures

The original research instrument requested demographic information for carer and child respondents pertaining to age, sex, and education, among other variables, while community infrastructural resources were captured on the economic asset index, providing case ranking across five poverty quintiles (PQs). For the purpose of analysis, PQs were collapsed into two levels – low PQ (1-3) and high PQ (4-5).

The Strengths and Difficulties Questionnaire (SDQ) is a 25-item screening tool for child and adolescent behaviour (4-17 years) (Goodman, 1997). In this study, the SDQ was applied to child self-report and carer report of child behaviour. The SDQ comprises the Total Difficulties Scale (20 items) which assesses four maladaptive behaviours related to Conduct Problems, Hyperactivity, Peer Problems and Emotional Symptoms, and a Prosocial Scale (5 items). The Prosocial Scale provides a measure of adaptive social functioning, with statements such as, “*Helpful if someone is hurt, upset or feeling ill*”. Participants respond to the Prosocial Scale on a 3-point likert scale (0=not true, 1=somewhat true, 2=certainly true). Scores may range from 0-10, with higher scores supporting more positive social behaviour. Child self-reports for the

Prosocial Scale in this study ($\alpha=.89$), yielded stronger reliabilities than previous investigations (.69-.82) (Deighton et al., 2014). Results for the carer report ($\alpha=.69$), were within an accepted range of previous utilisations (.63-.85) (Deighton et al., 2014). Respondent scores for the Prosocial Scale were compared with established clinical cut-off scores derived from British samples: average 6-10 (80% sample); borderline 5 (20%); and clinical 0-4 (10%) (Goodman, 1997).

Statistical Analysis

Data was analysed using the Statistical Package for the Social Sciences (SPSS), version 21. Frequency counts, means, standard deviations, cross tabulations and Chi-square statistics were calculated across variables of sex, carer education, the primary carer relationship and economics. The variable for “HIV-affected dyad”, as computed from verbal autopsy data, reflects a dynamic of child orphanhood (non-orphan, orphan due to AIDS, or orphan due to other reasons) and carer ill-health, resulting in six categories (see Table 1). The term ‘dual-affected’ refers to dyads where the primary carer is identified as unwell and the child is orphaned due to AIDS – the inverse of a ‘non-affected’ dyad. Correlational analysis was also employed to assess the consistency of ratings for Prosociality across carer and child respondents, as informed by Cohen’s (1988) criteria: <0.3 as small; ≥ 0.30 and <0.50 as medium, and ≥ 0.50 as strong.

Kruskal-Wallis tests with pairwise comparisons were conducted to contrast mean prosocial scores for children across the HIV-affected carer-child dyads (confidence level = .05), with cross-tabulation analysis employed to categorise carer and child prosociality ratings across clinical classification bands. Additional two-way between groups ANOVAs were conducted to examine the potential mediating role of sex or primary caregiver role on HIV-affected carer-child dyads, in regards ratings of child

prosociality. Finally, simple linear regressions were calculated to estimate the effect of select demographics on child prosociality scores for carer and child respondents.

Dummy variables for orphan status were computed and carer education was recomputed as a dichotomous variable (schooling/no schooling) to minimise multicollinearity.

Findings

Demographic Characteristics

The composition of the sample was predominantly Black African (99.8%) and first language isiZulu speakers (96%). The majority of carers were female (89.0% n=1901), with biological mothers (64.5% n=1377) and grandmothers (17.6% n=374) assuming responsibility of care, followed by biological fathers (4.4% n=95) and aunts (4% n=86). The age of primary carers ranged from 18 to 89 years (M=44.04; SD=13.58).

Approximately half the carers achieved a level of secondary education (51.9% n=1101), however nearly a quarter indicated no history of schooling (22.6% n=480). The age of child participants ranged from 10 to 17 years (M= 13.5; SD=2.23), with a slightly larger proportion of girls (53.7% n=1147) as compared to boys (46.3% n=988). More than half the children obtained a level of primary education (60.1%, n=1264) while a further 39.8% reported secondary schooling (n=837).

More than half of the sample were identified as non-affected (57.5% n=1228).

Of the remaining sample, many cases involved ill carers attending to non-orphaned children (19.6% n=418), followed by non-ill carers attending to children orphaned due to other reasons (9.9% n=211). The smallest proportion of cases were dual-affected (3.3% n=70). **A review of primary carers, reveal that grandmothers assume the major role in caring for children orphaned due to AIDS (dual-affected 22.9% n=16; and non-ill carer/orphan due to AIDS 40.4% n=46).**

Chi-square test for independence indicated a significant association between economic assets and carer-child dyad, ($F(5, 2136) = 66.286, p = .00$). Closer analysis reveals a higher proportion of ill-carers within the lower poverty quintiles (PQ 1-3): ill carer, no orphans (71.5% $n=299$), ill carer with other orphans (76.8% $n=73$) and dual-affected (82.9% $n=58$). The association with parental ill-health and poverty is supported by other research (Cluver et al. 2013). A Chi-square test also indicated a significant association between carer education and carer-child dyad, ($F(5, 2123) = 41.764, p = .00$), with nearly 40% of dual-affected dyads reflecting no carer education (37.1% $n=26$).

[Table 1. Demographic profile of primary carers and child respondents]

Prosocial Ratings across HIV-Affected Dyads

Children's prosocial self-report ($M=8.42$; $SD=2.53$) were on average consistently higher than the carer's report ($M=7.62$; $SD=2.35$) (see Table 2). Estimated reliability between carer and child respondents was 0.38, with 95% CI (0.34, 0.41), suggesting a small to medium level of agreement, as per Cohen's (1988) criteria. Results of the Kruskal-Wallis tests indicate statistically significant differences in carer ratings of child prosociality across groups, $X^2(5, 2136) = 16.76, p = .005$. Pairwise comparisons for the Prosocial Scale indicate only one significant difference between the non-affected group ($M = 7.52, SD = 2.37$) and cases with ill carers and non-orphans ($M = 7.96, SD = 2.11$). No significant differences were indicated across child reports. Furthermore, no significant interaction effects emerged across carer ratings of child prosociality between carer sex and HIV-affected dyads ($F(5, 2124) = 1.597, p = .157$) or child sex and HIV-affected dyads ($F(5, 2123) = .378, p = .864$); or for carer sex and HIV-affected dyads

($F(5, 2121) = .195, p = .964$) or child sex and HIV-affected dyads ($F(5, 2121) = .342, p = .888$) across child ratings. Additional Kruskal-Wallis tests indicate no significant differences in carer or child ratings of prosociality across primary carer groups.

Clinical cut-offs for the carer report, calculated at the 10th percentile, were consistent with British estimates (0-4, Goodman, 1997), with 12.5% (n=266) of children identified as clinically at-risk in terms of their prosociality. The highest levels of risk were recorded for dual-affected groups (18.6% n=13) followed by cases of non-ill carers and orphans due to AIDS (15.8% n=18). Carer responses reflected less clinical prosociality when ill carers attend to non-orphaned youth (7.4% n=31). Clinical cut-offs for the self-reported prosociality at the 10th percentile revealed a higher threshold (0-5) than British estimates (0-4, Goodman, 1997). Children reported the highest risk for clinical prosociality within non-affected groups (9.7% n=119) and lowest risk for dual-affected (2.9% n=2).

[Table 2. Carer and Child ratings (means, standard deviation) and clinical cut-off scores for Child Prosociality across HIV-Affected Dyads]

A Weighted Model of Prosociality

A simple linear regression was calculated to determine the effect of select demographics like child and carer sex, child and carer age, carer education, carer health, carer relationship to child, orphan status and economics on carer and child ratings of child prosociality (see Table 3). Carer education was statistically significant in distinguishing levels of child prosociality across carer report ($F(10, 2107) = 2.968, p = .004$). Findings suggest that less schooling were associated with high carer ratings of child prosociality. Economic indicators were also statistically significant in distinguishing

levels of prosociality across carer report ($F(10, 2107) = 2.968, p = .003$) and child report ($F(10, 2105) = 1.1420, p = .048$), with findings suggesting that ratings of child prosociality increase as poverty quintiles increase (PQ4-5). Although a small positive correlation exists between education and economics ($r = .194, n = 2131, p < .0001$), these factors appear to predict prosociality in opposing directions.

[Table 3. Simple Regression Analyses for Variables Predicting Carer and Child Ratings of Child Prosociality]

Discussion

Economic indicators and carer education were significant predictors of prosociality. Results support previous literature in suggesting that financial stressors may potentially hamper the warmth and expressiveness generated in carer-child relationships (Chase-Lansdale et al., 1995), or limit opportunities for carers to model the charitable behaviour that guides learned prosociality (Bandy and Ottoni-Wilhelm, 2012). For carer education, carers with higher education may impose stricter expectations of child behaviour, thereby leading to lower ratings of prosociality. However the relationship between poverty, education, and prosociality is complex and requires further investigation in terms of the mediating role of parental well-being and the nuances surrounding structural and household resources.

The examination of mean prosociality scores suggests that carer ratings may differ across carer health, with ill carers more likely to report higher child prosociality across contexts. Depending on the extent of illness, carers diagnosed with HIV may experience physical and psychosocial difficulties that require more active assistance from children in the home (Bauman et al., 2006; Harms et al., 2010), resulting in a

greater acknowledgement of these prosocial tendencies. The greatest perceived risk of clinical prosociality by carers was for children orphaned due to AIDS. As grandmothers assume a more dominant role in caring for these groups, prosociality ratings may be impacted by generational views of child behaviour. However as no significant differences in prosociality were noted across primary carers, differences may relate to experiential factors surrounding parental loss due to AIDS, like stigma or unresolved grief, that negatively impact carer's perceptions of child prosociality.

For child respondents, the mean distribution of scores suggest that orphaned youth, regardless of circumstances behind parental death, assign higher self-ratings of prosociality than non-orphaned youth. Orphaned youth may regard themselves as more prosocial in light of the heightened emotional sensitivities and domestic responsibilities they incur prior to and following the loss of parents (Betancourt et al., 2011; Skovdal and Ogutu, 2009). Self-recognition of prosociality is a promising finding, particularly in contexts of risk, where it may translate into more adaptive and resilient capabilities (Theron and Theron, 2010; Ungar, 2008). However, this hypothesis requires further investigation, as differences in this study did not reach clinical significance.

Furthermore, self-report within dual-affected dyads showed the least risk for clinical prosociality (2.9% n=2), thereby contradicting carer ratings. These low proportions were consistent with at-risk samples involving residential street children in Zambia (3.2% n=2; Imasiku and Banda, 2010) and HIV-affected youth in Ghana (children orphaned due to AIDS, 3.5%, n=7; children living with parents infected with HIV/AIDS, 4% n =2) (Doku, 2010).

Overall, levels of agreement between carer and child respondents were low but consistent with British community samples (0.31, Goodman, et al., 1998). Previous studies have shown discrepancies across mother and child ratings of prosociality (Hay

and Pawlby, 2003) and accounts of household responsibilities (Bauman et al., 2006), particularly when carers are inflicted with some form of ill-health. Although rater differences in this study did not reach clinical significance, inconsistencies highlight the potential fragility and misunderstanding emerging within strained contexts, where physically and psychologically compromised carers may minimise the prosocial achievements of children orphaned due to AIDS. These inter-rater discrepancies provide further support for multi-informant design in screening for mental health risks.

Application of community classification bands identified a slightly higher number of cases at clinical levels of risk according to carers, as compared to the child self-report which yielded lower cases than the 10% British estimate. Although social desirability may explain a tendency for children to exaggerate prosociality, the high consistency in child response suggest that carers and children may draw on different definitions of prosocial behaviour (Hay and Pawlby, 2003; Williamson et al., 2014). Furthermore, differing levels of clinical risk in this study may be explained cross-culturally through collectivist orientations that view helping others as a duty rather than a personal choice (Skovdal and Ogutu, 2009).

Despite the popularity of the SDQ within research literature, relatively less attention has been granted to the performance of the Prosocial scale, thereby limiting comparative analysis. Those studies employing the Prosocial scale have noted the potential to provide greater insight into appropriate child behaviour across cultures (Williamson et al., 2014). However, limitations are noted in the use of a single (5-item) instrument, despite the adequate psychometric properties in this sample. The three-point Likert scale design limits variability in data, and may not be sensitive to detect changes over time (Deighton et al., 2014). Furthermore, cross-sectional studies do not provide a longitudinal perspective on psychosocial adjustment (Sherr et al., 2014). This

is significant as the length of time since parental loss may impact the child's emotional and behavioural needs at the time of assessment.

This research supports the understanding that narrowly focusing on orphaned youth in policy and intervention, and ignoring the role of parental ill-health, may undermine the needs of other HIV-affected groups. Previous research amongst HIV-affected youth has been preoccupied with a deficits approach and largely ignored or minimised children's adaptive capabilities in the face of adversity. Further research is needed to explore child prosociality as a protective mechanism in high HIV-endemic communities. However noting previous work by resiliency researchers, further research is needed to better understand the cultural and contextual sensitivity of the construct. Developing a better understanding of how youth construct resilience and how to rigorously measure this construct can assist in the development of behavioral interventions to support resilience (Ungar, 2008). Understanding psychosocial resilience is vital to support children and families affected by HIV and AIDS.

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