How supportive is the social network of AIDS orphans and other orphaned children in Conakry and N’Zérékoré, Guinea?

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In the shadow of sub-Saharan Africa’s deplorable AIDS-related mortality rates lies a statistic that is potentially more alarming: in 2010, sub-Saharan Africa was home to an estimated 18.4 million children orphaned by HIV/AIDS. In the absence of universal access to antiretroviral treatment (ART), the number of AIDS orphans is expected to rise to 40 million by 2020 (1). With an estimated HIV prevalence of only 1.6%, Guinea is a relatively ‘soft case’ compared to most other sub-Saharan countries (2). Yet Guinea is currently home to at least 41 000 AIDS orphans (3), and the rate at which children are orphaned by AIDS is unlikely to decrease in the near future, given that the coverage of ART was estimated at only 27% in 2007 (4).

Social and psychological well-being of orphans

Few children in sub-Saharan Africa live in luxury, yet it is recognized that AIDS orphans face far greater financial, educational and psycho-social challenges to their development than their peers with healthy living parents (5). Development organizations and research institutions have traditionally focused their efforts on the physical and material needs of these orphans (6). In contrast, efforts to measure and counteract the impact of parental bereavement on children’s social and psychological well-being have only commenced recently (7). Anecdotal reports indicate that AIDS orphans often lack social support and that abuse and neglect of children orphaned by AIDS by both the extended family and the broader community is not uncommon (8).

A cross-sectional survey was conducted in August-September 2006, assessing the level and nature of abuse and neglect experienced by AIDS orphans (10-18 years) in Conakry and N’Zérékoré, Guinea. Additionally, the degree of perceived social support was explored in children whose parents were still alive and not perceived to be HIV positive (NO) (n=140), children orphaned by causes other than AIDS (O) (n=133), and children orphaned by AIDS (O-A) (n=133).

High rate of abuse and neglect

The study demonstrates that acts of abuse and neglect towards AIDS orphans are disturbingly common in Conakry and N’Zérékoré. Seven to eight in ten children reported having been abandoned, criticised/insulted or neglected, and three to four claimed to have been mistreated or malnourished. Similar findings of high levels of discrimination against AIDS orphans have been found in Malawi, Uganda and South Africa (9, 10, 11). It was found that the very people whom one would expect to support AIDS orphans – close family members, guardians and other relatives – are not seldom deemed responsible for acts of abuse and neglect (Figure 1), although neighbours and other members of the community were most often indicated as committers.

This observation chimes with the finding that levels of perceived social support, especially from family members, are lower in O-A than in O and NO. The results of a multiple ordinal logistic regression are presented in Table 1.

In line with previous findings from South Africa, the survey indicates that AIDS orphans have sparse social networks of friends (12). More than a quarter of O-A reported having no friends at all, and a much higher proportion of O-A than other children claimed to have difficulty making friends or being accepted by friends.

Stigma as a central factor

These findings have important implications for the design, implementation and evaluation of interventions aimed at safeguarding or improving the psychosocial well-being of AIDS orphans. Firstly, such interventions should take into account the interrelated nature of AIDS-related stigma, social support and psychosocial outcomes. Recent studies are pointing to HIV/AIDS-related stigma as a central factor in mediating the associations between AIDS orphanhood and levels of perceived social support, psychosocial disorders, discrimination, and acts of abuse and neglect (10). Stigma often precludes adequate family and community support as (potential) caregivers of AIDS orphans face stigma and discrimination as well (13). In addition, families caring for children orphaned by AIDS may have internalised stigmatising attitudes towards AIDS-affected children (14). Lower levels of perceived support have in turn been associated with social discrimination and child abuse (11), and psychosocial distress (15). The data of the current study confirm these associations and show that AIDS orphans feel stigmatised and discriminated against, not only by neighbours and other members of the wider community, but also by guardians, teachers, relatives and other children of the care taking family. As a consequence, community-based and governmental initiatives to reduce stigma and discrimination against children orphaned by AIDS must penetrate into the family sphere. Current initiatives, which mainly make use of public information campaigns and community debates generally focus on changing attitudes in and protecting children from the wider community.
Table 1. Estimated adjusted proportional odds ratios for types of perceived support

<table>
<thead>
<tr>
<th>Support by family members</th>
<th>O</th>
<th>NO (95% CI)</th>
<th>O-A (95% CI)</th>
<th>P value (likelihood ratio test)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support by external people</td>
<td>1</td>
<td>1.03 (0.60 – 1.75)</td>
<td>0.80 (0.46 – 1.39)</td>
<td>0.55</td>
</tr>
<tr>
<td>Support by the community in general</td>
<td>1</td>
<td>1.70 (0.87 – 3.34)</td>
<td>0.56 (0.24 – 1.29)</td>
<td>0.22</td>
</tr>
<tr>
<td>Support by the religious community</td>
<td>1</td>
<td>1.21 (0.61 – 2.37)</td>
<td>0.37 (0.56 – 0.88)</td>
<td>0.003</td>
</tr>
</tbody>
</table>
Secondly, operational research of the effectiveness, scalability and affordability of interventions to reduce AIDS-related stigma and increase social support for children orphaned by AIDS is much needed. While governments, non-governmental organisations, faith-based organisations and clinicians have launched many programmes to support AIDS orphans, other vulnerable children, and their care givers, current practice is based on anecdotal knowledge, descriptive studies and situational analyses, rather than rigorously tested interventions (16).

Lastly, it is important to note that the survey reaffirms that AIDS orphans are not the only vulnerable children in poor AIDS-affected communities: lack of support and sparse social networks of friends were also reported by at least some non-orphans and non-AIDS orphans. Welfare interventions must therefore target all vulnerable children, not just those orphaned by AIDS, as singling out AIDS orphans for special treatment may aggravate stigma and discrimination (17). This implies that governmental and community-based organisations committed to the social welfare of children should consider targeting communities rather than individual households if social vulnerability is widespread in the community and not only related to HIV/AIDS (18).

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References: