Breaching cultural silence: enhancing resilience among Ugandan orphans

Marguerite Daniel*, Hellen Malinga Apila, Rune Bjørgo and Gro Therese Lie

Research Centre for Health Promotion, Christiesgate 13, 5015 Bergen, Norway
* Corresponding author, e-mail: marguerite.daniel@iuh.uib.no

Cultural silence is frequently the outcome of deep-seated taboos regarding adults talking to children about sex and death. This paper examines the impact of cultural silence on the resilience of children orphaned by AIDS in Uganda. Cultural silence is often linked with denial. This article explores the complexities of cultural silence in terms of its causes, justifications and impacts. The findings from two small, in-depth qualitative studies among orphans who were being supported by community-based organisations in Kampala illustrate the impacts of cultural silence and disclosure on the coping ability of orphaned children. The first study involved 11 children orphaned by AIDS (four boys and seven girls, aged 12 to 17 years) and four parents widowed by AIDS (two men and two women) who were themselves living with HIV. (None of the parents interviewed were related to the orphans in the study.) In the second study, 10 HIV-positive mothers (aged 25 to 40) and nine children (six boys and three girls, aged 11 to 18) with HIV-positive mothers were interviewed. The discussion examines the findings by using a model of resilience, centred on the concepts of closeness and competence as conditions for coping. Cultural silence emerges as a risk factor that increases children’s vulnerability through undermining both closeness and competence, while disclosure and openness — the breaching of cultural silence — are revealed as protective factors that may enhance resilience among children.

Keywords: Africa, children and youth, community-based organisations, coping behaviour, cultural aspects, disclosure, HIV/AIDS, psychosocial aspects, qualitative research, taboos

Introduction

Sex and death are taboo subjects in many cultures, and the AIDS epidemic, with the sexual transmission of HIV infection and the impact on the death rate, has brought attention to these sensitive issues. Historically, children in many southern African countries have been excluded from funerals and might not even be told about the death of their parent because of a cultural understanding that death is too traumatic for children to withstand (Ndudani, 1998; Rantao, 2002). Nndudani (1998) attributes this to the belief that death is regarded as a sort of pollution that has harmful effects on the bereaved, particularly children. In contemporary sub-Saharan Africa such ‘cultural silence’ is still a widespread norm. At an explicit level, culture is frequently used as an explanation for silence: “In our culture we do not talk to children about death, they are too young to understand” (Daniel, 2005b, p. 28). In many cases after a death no one explains to children what has happened and if they ask they may only be told they will understand when they are older (Daniel, 2005b). A different reason for silence is given in a paper about East Africa by Sengendo & Nambi (1997): those authors report a cultural belief in Uganda that children do not have emotional problems. Adults do not always talk and listen to children and therefore do not understand that they may be affected by bereavement (Sengendo & Nambi, 1997).

In sub-Saharan Africa, where millions of children have experienced the death of one or both parents, the scale of orphaning is great. In 2003, 12.3% of all children under age 18 in sub-Saharan Africa were orphans, and in 11 of the 43 countries in the region more than 15% of children were orphaned (UNICEF/UNAIDS/USAID, 2004). The projected number of orphans is expected to continue to grow until at least 2010, and in those countries with HIV prevalence exceeding 30%, more than one in five children are likely to be orphaned by 2010 (UNICEF/UNAIDS/USAID, 2004). To date, extended family networks in sub-Saharan Africa care for more than 90% of orphaned children, but as more adults are affected by HIV this safety net is coming under increasing strain (UNICEF/UNAIDS/USAID, 2004). In the context of AIDS, bereaved children may suffer multiple losses — such as the death of their parents and perhaps a younger sibling, separation of surviving siblings, interrupted education, migration and a move to unfamiliar surroundings with a new caregiver, or the loss of status and the associated dreams about what they would one day achieve. A child may grieve and mourn each of these losses. Unfortunately, there is a dearth of literature on the experiences of grief of African children within their own cultures (Foster, 2002; Bray, 2003).

It has been widely reported that Uganda was one of the first countries in sub-Saharan Africa to have experienced high prevalence and a high proportion of HIV/AIDS-related deaths beginning in the 1980s. However, it must be noted that most of the data are limited to southern Uganda (partic-
ularly the Masaka and Rakai districts) and thus cannot be

generalised for the whole country (Allen, 2005). Although

Uganda is one of the few countries that has succeeded in
dramatically reducing HIV prevalence, levels of orphaning
will remain high for some time due to the time lag between
HIV infection and AIDS-illness (Christiansen, 2005).

There are currently about two million orphans in Uganda,
constituting about 14% of all children in the country
(UNICEF/UNAIDS/USAID, 2004). An orphan can be
defined in numerous ways but for the purposes of this
paper the definition used is: a child below the age of 18
years who has lost one or both parents (Wakhweya,
Kateregga, Konde-Lule, Mukyala, Sabin, Williams &
Heggenhougen, 2002), which is the definition used by the
Ugandan government and most NGOs in Uganda. Histori-
cally in Uganda orphans have been cared for by the
extended family. However, the ability of the extended family
to continue to absorb orphans and to cope with the burden
of caring for additional children has been severely reduced
by the scale of orphaning and, increasingly, children are
divided up between relatives or may stay by themselves in
an orphan-headed household (Luzze, 2002; Luzze &
Ssedyabule, 2004). Communication between parents and
their children about AIDS-illness is typically limited because
of cultural norms and taboos surrounding sexuality and
death (Asera, Bagarukayo, Shuey & Barton, 1997). AIDS is
associated with death, sex, shame, social stigma and
rejection (Lie & Biswalo, 1996b; Bond, Chase & Aggleton,
2002; Duffy, 2005). Consequently, the adults' psychosocial
need to maintain confidentiality can overwhelm the need for
open dialogue with children about their parent's HIV-status
and the implications for the children's future. This, in turn,
makes it more difficult to provide adequate counselling and
support for children.

The Ugandan government has made a concerted effort to
deal with issues of child welfare by providing free primary
education and by acceding to the UN Convention on the
Rights of the Child (CRC). Uganda adopted a National
Orphans Policy in June 2005, and while the guiding princi-
pies do not specifically include the encouraging of disclo-
sure, the core programme areas do refer to psychosocial
support in general (Kaboggoza-Ssembatya, 2006). In
addition to major international institutions such as UNICEF,
many humanitarian development agencies and religious
groups have established programmes in Uganda or
financially assist local NGOs and community-based organi-
sations (CBOs) that provide services for children. However,
given the scale of orphaning in Uganda, these programmes
ultimately reach only a small proportion of those in need
(Christiansen, 2005).

AIDS Widows Orphans Family Support (AWOFS) is a
CBO centred at St. Francis Hospital,Nsambya,Kampala.
It is involved in mitigating the impacts of the epidemic by
providing services directly to widows,orphans and
grandparent-headed households affected by AIDS. Its
services include micro-credit loans accompanied by some
project management training, counselling for orphans,
behaviour-change seminars, and legal services to help
widows and orphans with the transfer of family property.
The biggest challenge for the organisation is how best to
meet the vast range of material and emotional needs given
their limited resources.²

The National Community of Women Living with HIV/AIDS
(NACWOLA) is a much larger organisation operating in 23
of Uganda's districts. Its main objectives include fighting the
stigmatisation of women living with HIV and empowering
them with income-generating projects to reduce their
vulnerability and dependency. In addition, it aims to give
psychological support to women living with HIV and to
empower their families, especially children, with coping
mechanisms for the future. NACWOLA's Memory Project
responds to difficulties experienced by parents and children
living in HIV-affected families. It aims at empowering HIV-
infected parents to assist their children to prepare for and
survive parental loss. Parents are supported through training
to disclose their HIV status and ill health to their
children, for the future by establishing child guardian-
ship arrangements, and provide documentation of important
family history and precious memories in the format provided
by the memory book. NACWOLA provides legal assistance
for the preparation of valid wills and works with children
to enhance their understanding and acceptance of HIV and
AIDS in the family.³

Theoretical context and literature review

This paper explores the results of two studies conducted
with orphaned children in Kampala. When the findings of
the two studies were examined alongside one another, it
became clear that they enhanced the critical understanding
of the impact of cultural silence from two contrasting
positions: without disclosure and after disclosure. In the
next section we examine the literature on the concept of
cultural silence and denial, particularly in the context of HIV.
We then consider the impact on children of silence and
secrecy, as it has been discussed in the literature, as well
as the concept of resilience and the impact of cultural
silence on protective factors.

Cultural silence

Cultural silence is based on deep-seated cultural taboos
regarding adults talking to children about sex and death,
partly due to rules of respect that underlie family and
kinship structures and which may limit communication
across generation and gender divides (Caldwell, 2001;
Allen & Heald, 2004). Historically children were taught
about sex, sexuality and sexual relationships by elders or
other nominated persons, specifically during initiation
(Fuglesang, 1997; Geiser, 2000; Sackey, 2001; Wieringa,
2001); parents and other (non-designated) adults did not
necessarily talk to children about sex (Asera et al., 1997;
Fuglesang, 1997; Sackey, 2001). Likewise, adults did not
talk to children about death, and, as mentioned, children
were usually excluded from funerals until they had been
through initiation, after which they were considered adults.
Given the current high numbers of deaths due to AIDS-
ilness, and because of HIV transmission through sexual
behaviour, cultural silence could now be said to involve an
element of denial which may be harmful to children. In
many sub-Saharan African countries, while the taboos on
talking about sex and death remain in place, initiation practices have been eroded or abandoned; in many cultures children no longer experience a formal transition to adulthood nor do they receive adequate education and information about sex (Fuglesang, 1997; Geiser, 2000; Herdt, 2001; Wieringa, 2001). Many of the countries severely affected by AIDS, particularly those in southern Africa, are experiencing rising rates of rape and sexual violence (Leclerc-Madilaia, 2001; Van Rensburg, Ngwena, Pelsier, Steyn, Booyse, Friedman & Ardendorff, 2002). Therefore, denying children information about sex and the opportunity to ask questions and discuss sexual matters may raise the level of risk that they face.

Similarly, in an era of AIDS, cultural silence about death is also closely linked with denial; in fact, it may be described as a passive form of denial, a hiding behind culture, a denial of responsibility. Adults’ silence towards children about death and loss may be ‘excused’ by saying that “in our culture we don’t talk to children about death.” This is expedient because it is easier to remain silent than to explain death to a child in terms that are comprehensible at a child’s particular level of cognitive development. Cultural silence involves elements of complicity and collusion — but not of conspiracy: the adults have not set out to deliberately harm the children, although the ultimate effect of the silence may well be damaging4 (Daniel, 2005b).

One of the strongest reasons for silence at the cultural level, across the whole community or society, is that the group “learns to keep silent about matters whose open discussion would threaten its self-image” (Cohen, 2001, p. 11). Bystanders might refuse to believe what they are witnessing because if it was true it would seriously threaten their sense of personal and cultural identity. For instance, if several people in the community are HIV-positive or have visible symptoms of AIDS-related infections, what does it imply about the community? And, how does it affect the community’s image of itself? The ideal cultural image is of a society with faithful relationships within stable marriages, but AIDS is associated with promiscuity, sex, death, stigma and shame (Lue & Biswalo, 1996b; Bond et al., 2002; Duffy, 2005). Societies reach unwritten agreements about what can be openly acknowledged and anyone breaching the agreement becomes the offender. Where individuals or families are infected or affected by HIV or AIDS, it may be ‘known’ yet not publicly acknowledged — and someone breaking the taboo could be regarded as starting a witch-hunt. Codes of silence and webs of complicity may ensnare those who are infected and affected as well as those who are bystanders — into colluding in silence about issues that threaten the group’s concept of itself. ‘All’ that they are required to do is to keep up an appearance of normality, to live as if what is happening is not happening (Good, 2000; Cohen, 2001). Muyinda, Seeley, Pickering & Barton (1997) reported that patients and their families commonly denied symptoms of HIV infection, and that, in spite of the physical signs, as long as the infected person behaved as ‘normally’ as possible they would remain socially acceptable.

Cohen (2001) argues that people who suffer from something terrible happening or being done to them may use clichés (e.g. ‘This can’t be happening to me’) in order to keep disturbing knowledge away from themselves. The author goes on to say that this can apply at a cultural level too. Even when the warning signs are clear, whole groups may deny their approaching fate. Where those affected then fail to protect themselves against whatever is threatening them, it can be disastrous. However, in some situations denial is healthy and adaptive: it allows life to continue amid high levels of stress. Denial in the context of HIV and AIDS is a mixture of the two. It is disastrous because some people do not change their behaviour in spite of clear warning signs and well-informed knowledge about the condition, but it is adaptive in that it allows life to continue even where there are high levels of HIV infection and rising numbers of AIDS deaths that cause dislocation and almost intolerable stress to the community. In the case of many adults, cultural silence falls into the adaptive category, as it allows those infected and affected to continue to live in spite of the stress brought on by the knowledge of their status. However, in the case of children, cultural silence often adds to the burden of stress they bear.

The impact of silence and secrecy5

The literature on the impact of silence and secrecy on children is overwhelmingly generated in North America and Europe. Lewis (1995) argues that if a child’s questions are discouraged or not answered, the child may ‘fantasise’ answers that are more frightening than the real ones. Then, when a real event, like death, mirrors such a fantasy, the child’s level of anxiety may increase suddenly. Children usually hesitate to share fantasies or memories of their dead parent with other children for fear of being teased, and these feelings, as well as emotions such as anxiety, anger and loneliness, may also become secret. Children who are not given sufficient opportunities to share feelings or who are actively blocked from expressing their emotions may resort unconsciously (or even consciously) to behavioural manifestations of their anxiety, frustration and anger.

Nagler, Andropoz & Forsyth (1995) worked with children and families affected by AIDS in New Haven, Connecticut. In their experience, many people affected by AIDS take on the associated stigma as part of their own sense of identity. Their resulting self-concept as unwanted and unloved contributes to their fear of disclosing the secret of their HIV infection and their response becomes one of secrecy and denial. This internalising of the stigma occurs when individuals incorporate standards from the wider society, making them more vulnerable to feelings of self-hatred (Lee, Kochman & Sikkema, 2002). Cree, Kay, Tidsall & Wallace (2004) state that another reason for parents’ reluctance to disclose their HIV status to their children is because they fear that children cannot keep secrets. The physical effects of AIDS-illness are, however, undeniable, and so the results of these protective attempts is “to render the disease unnamed, unspoken and often unspeakable to children who then have no name for what they know is happening to their loved ones and to themselves” (Nagler et al., 1995, p. 75).

Nagler et al. (1995) conclude that the issue of secrecy is more about naming than about knowing: even when children have not been told, it would be inaccurate to say
they don’t know. Indeed, they know that something is terribly wrong but it is something for which they cannot use the name; it literally becomes the ‘nameless dread.’ Without a name, children are unable to use language and words to help them understand and cope with frightening fantasies and painful realities. Knowing the name, but not having permission to use it, puts children in the situation of feeling they are defying and being disloyal to their parents every time they have a clear thought about their position. In the experience of Nagler et al. (1995), once children have the name, they do not necessarily use it much; most children will keep the secret as their parents and society have taught them. Although this protects the family from stigma, it also prevents the child or adolescent from receiving clarification, validation and support, which in the long run may threaten their psychological growth, impede their developmental progress, and interfere with their ability to cope in all the important areas of their lives.

Another study, in Uganda, by Gilborn, Nyonyintono, Kabumbuli & Jagwe-Wadda (2001), found that the experiences of African children whose parents were sick with AIDS closely matched those described above. Among 181 older children participating in the study, about 82% were aware that their parent had some health problem but only about 28% reported that their parent had told them they were HIV-positive. Of those who were told, the vast majority (88%) said it was a good idea for parents to disclose their HIV status to their children. Children who had already been orphaned also participated in the study and only 19% of them reported having discussed their parent’s HIV status with them. Both those who had experienced parental disclosure and those who had not, were in favour of disclosure.

In the era of AIDS, silence and secrecy about death and illness may increase the physical and psychosocial vulnerability of affected and bereaved children. Vulnerability is associated with risk factors, and cultural silence may be seen as an additional risk factor. Hence, breaching cultural silence may be seen as a protective factor enhancing a child’s resilience.

Resilience

Luthar, Cicchetti & Becker (2000, p. 543) define resilience as “a dynamic process encompassing positive adaptation within the context of significant adversity.” The emphasis on resilience represents a shift in thinking about childhood away from focusing on vulnerability to give a more contextualised understanding of children’s responses to adversity (Evans, 2005). Rutter (1990) points out that vulnerability and resilience are two poles of the same concept. Resilience is not a fixed attribute of the individual, rather it is enhanced by the presence of one or more protective factors, such as close relations with competent and caring adults in the family and community, a range of problem-solving skills, self-esteem and self-confidence (Howe, Brandon, Hinings & Schofield, 1999; Rutter, 1999; Luthar et al., 2000; Masten, 2001; Gilligan, 2001 and 2002; Evans, 2005).

Sommerschild (1998) developed a model that bases the conditions for coping on closeness and competence. Rutter (1985) argued that there are two kinds of experiences that foster a protective self-concept: the presence of a secure intimate relationship with another person and the experience of success in one area or another. These two experiences may be regarded as equivalent to the constructs of closeness and competence (Fjermestad & Kvestad, 2002). Closeness is examined at the different levels of caregiver, family and community. The importance of having a close relationship with at least one significant other is frequently referred to as an important protective factor in a child’s life (Rutter, 1985; Fonagy, Steele, Steele, Higgit & Target, 1994; Sommerschild, 1998; Goldberg, 2000). Sommerschild (1998) describes a close relationship as one based on trust, openness and mutuality. Research with children who display resilience has shown that there is at least one person who accepts them unconditionally and who promotes resilience — not by removing stress and adversity from the child’s life, but by helping the child to encounter gradual challenges that enhance competence (Werner, 2000). Social networks are not necessarily supportive, so it is necessary to distinguish between social networks per se and the phenomenon of social support, which includes approval, emotional and instrumental support. Perceived social support is the subjective appraisal of support and is generally associated with resilience in both adults and children (Robinson & Garber, 1995; Fjermestad & Kvestad, 2002). In Sommerschild’s model (1998) competence refers to being able, being of use, receiving and taking responsibility, displaying love for another, and encountering and handling adversity. Other authors refer to competence as the capacity to cope with opportunities, challenges, frustrations and threats in the environment (Masten & Coatsworth, 1995; Walsh, 1999). Sommerschild (1998) links the successful fulfilment of these conditions with the outcomes of self-worth and resilience.

When examining the impact of cultural silence — or the breaching of cultural silence — on resilience and a child’s ability to cope with bereavement, Sommerchild’s (1998) model provides a useful framework. Cultural silence may damage trust in relationships with caregivers as well as those within the extended family and the community. When a child knows that his or her parent is suffering from an AIDS-illness or has died of one, yet they are not allowed to acknowledge this or to ask questions, cultural silence becomes an additional risk factor, co-occurring with other risk factors (such as deepened poverty due to the parent’s illness and death), and that increases the general vulnerability of the child. On the other hand, breaching cultural silence may enhance resilience by promoting trust and openness in close relationships, and simultaneously improving competence by allowing the child to express love by helping to care for the ill parent (which involves being able, being of use and taking responsibility) while encountering and handling adversity.

The studies

The findings of two small, in-depth qualitative studies among orphans supported by CBOs in Kampala illustrate the effect of cultural silence — and breaching cultural silence through disclosure of HIV status — on the coping ability and psychosocial well-being of orphaned children.
One study (Study A), by Apila (2003), took place from May to August 2001; it involved 11 children (four boys and seven girls), aged 12 to 17 years old, who had been orphaned by AIDS (Table 1), and four parents (two men and two women), all widowed by AIDS and who were themselves living with HIV. None of the parents interviewed were in any way related to the orphans in that study. The participants were all identified by the CBO called AIDS Widows Orphans Family Support (AWOFS). In-depth interviews (lasting between one and one-and-a-half hours each) explored the children’s feelings concerning their parent’s illness and death as well as communication between children and their parents on HIV/AIDS-related issues. Also, the director of AWOFS and two counsellors joined in a group discussion to provide background information on the organisation.

Another study (Study B), by Bjørgo (2001), took place between December 2000 and July 2001, with interviews in June and July 2001. Ten HIV-positive mothers, aged 25 to 40 years, and nine children (six boys and three girls), aged 11 to 18 (Table 1), whose mothers were HIV-positive were interviewed. All those participants were members of NACWOLA’s Memory Project and were identified by NACWOLA staff. Two of the adult participants were so ill that they had to be interviewed at home.

In both studies the recruitment criteria included that the children be linked to the respective CBO so that a CBO officer would be available should follow-up be necessary, even after the researcher had left. In addition, all the interviews took place in the building housing the CBO so that support was available should the child become upset during the interview.

In both studies the samples were purposively selected with the help of the respective organisations. The orphans interviewed were between the ages of 11 and 18 years. In Study B, the researcher and NACWOLA officials discussed whether or not to interview 11-year-olds, and, despite reservations, decided to include them. However, the younger children’s responses to the questions were minimal. This seemed not because of a language barrier, but because of the sensitivity of the subject and the fact that those children had not participated in the Memory Project for as long as the others. The findings of Study B therefore are effectively based on the responses of 12–18-year-olds and may not be applicable to younger children. The interviews conducted in both studies were semi-structured (interview guides were used) but the questions open-ended and there was opportunity to explore the children’s feelings and responses. All interviews were tape recorded and later transcribed. The text was analysed using a phenomenological-inspired method (see Van Manen, 1990; Kvale, 1996). After several readings of the material, key concepts were identified as central, and sub-themes were coded and collected into meaning units.7

The original two studies (by Apila [2003] and Bjørgo [2001]) were done inductively. When comparing the studies, interesting parallels emerged, and Sommerchild’s (1998) model seemed to be a functional theory for understanding the phenomenon of cultural silence; the two studies were revisited deductively to explore Sommerchild’s constructs. Citations used in this paper were selected because they typically portray the central themes presented by the children and caregivers in the two studies.

Ethics

Ethical clearance was obtained from both the Norwegian and Ugandan authorities and the research was carried out in the context of The Frame Agreement between the University of Bergen and Makerere University. Informed written consent was obtained from each of the participating caregivers on behalf of themselves and the child in their care after information about the research had been given. This information was repeated before each of the interviews and the informants were given the opportunity to withdraw from the study at any time should they wish to do so. The anonymity and confidentiality of the informants were ensured, both in writing and verbally. In addition, the researchers were continually aware that it might be painful for both children and adults to discuss issues that are personally and culturally sensitive. For this reason, the informants had been recruited through a community organisation. All the participants were well known to the AWOFS or NACWOLA staff and thus a support structure was in place should follow-up be necessary.

The findings

Cultural silence

Communication between parents and their children in Uganda about HIV/AIDS-related issues is not common, largely because of deep-seated cultural taboos about adults talking openly with children about sex and death, and the association of HIV with shame, social stigma and rejection. A father of eight children, widowed and living with HIV, responded to being asked about whether he had disclosed his HIV status to his children:

‘When we tested positive with my wife, I didn’t have that time to tell my children that we were sick, because there is no way you can tell a child that you are infected. The child will think that how did my father get that infection? Because that is stupidity! You can’t talk sex affairs with the children. It is obvious here in our culture, those affairs I would call

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Table 1: Age and gender of the children involved in the studies used in this work

<table>
<thead>
<tr>
<th>Age of children (years)</th>
<th>Study A*</th>
<th>Study B*</th>
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<tbody>
<tr>
<td></td>
<td>Study A</td>
<td>Study B</td>
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<tr>
<td></td>
<td>Boys</td>
<td>Girls</td>
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<td>Total</td>
<td>11</td>
<td>9</td>
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</tbody>
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* Study A: Apila (2003); Study B: Bjørgo (2001)
it even internal, those are internal affairs, which should not be known even to neighbours. It is very confidential, you must be confident that you reveal that secret to very few people. But it is stupid to tell children such affairs’ (Study A: Apila [2003], pp. 50–51).

This man has identified the cultural aspect of his silence and the taboo on adults talking about sex with children.

However, there is even silence between adults concerning HIV status, as shown in this quote from an interview with a widow:

‘I knew it in a way when my husband died. I suspected my man died of HIV, even he did not tell me. But I suspected because the way he was sick. That was in 1990. I decided to go for a check-up. I went for that check in 1991. They found out I had HIV and told me to join the homecare at Nysambya Hospital. But I kept quiet the whole of 1992. In 1993 I decided it was not useful to keep myself at home because I used to cry at home’ (Study B: Bjørgo [2001], p. 19).

The same woman goes on to give a possible reason for the cultural silence of widows. She describes making the decision to disclose her HIV status to her children after receiving training from NACWOLA, and explains:

‘For my children, I was afraid they would say — You are going to die, it was dad who brought you HIV, now I am also infected — something like that’ (Study B, p. 20).

Other widows belonging to NACWOLA expressed the same concern that their children would blame their father for infecting their mother and hence lose respect for their late father. Widows, although they themselves may have been ‘victims’ of cultural silence, justified their own silence towards their children by stating they did not want their children to think badly of their late father:

‘…I can answer them in a way that they do not need to hate their father’s grave or my in-laws like their uncles. Their aunts and uncles said it was my fault. It was a rough way, they can hate even though they are in the family’ (Study B, p. 49).

Another widow described making up a ‘suitable story’ because she could not tell her children that their father had infected her. These widows are truly ensnared by the codes of silence and webs of complicity governing their lives (Cohen, 2001). Stigma, shame and fear of rejection all impel those who are HIV-infected towards silence rather than disclosure.

However, even when parents do not disclose their illness to the children, the children may know something is wrong. For example, they know the symptoms of HIV-related infections and they often hear about their parent’s status from neighbours. A 17-year-old boy from a child-headed household said:

‘Being an orphan and knowing that my parents died of AIDS made me feel different from other people. And some people were eliminating [isolating] me. Our parents did not tell us about their sickness, we knew the stuff by ourselves. My father stayed with the disease for almost two or three years at home, but he didn’t tell us anything, but mum knew and the people around the area knew. For my case, I didn’t know until one day a lady in the neighbourhood whispered to another neighbour that the father has got the disease [AIDS]. I got to know, I knew everything because I had learnt at school that a person with this disease looks like this, and really felt it and it hurt me [at this point he wept]. But after my father’s death, our mother sat with us and told us except our last-born who was not at home that she had got the disease. When she told us, I wasn’t shocked because for me, although she had not said it to us, I knew it’ (Study A, p. 52).

This boy echoes the point made by Nagler et al. (1995), mentioned above, that even when children have not been told it would be inaccurate to say they don’t know. The boy’s words also indicate some of the additional risk factors that emerge from cultural silence: the isolation, stigma, loneliness and hurt he experienced when interpreting for himself what he had learnt at school and applying it to his own father.

A widow, living with HIV and a mother of six children, put it this way:

‘When a child knows that a parent is sick, the child knows it is the beginning of a hard life, a life without peace and joy. The child meets people in the community who keep gossiping about the sick parent — that so and so has AIDS. As a result, the child is not free and comfortable in the community and among other people. Such a child leads an unhappy life, feeling heart-broken for the rest of his or her life. It is not necessary to tell children about a parent’s sickness, because then the child begins to worry about the future. When a child gets to know that a parent is sick, the child understands that for him/her this could be the end of the world’ (Study A, p. 37).

Although the mother in this quote is justifying not disclosing to children, she also acknowledges that the child might hear about the parent’s HIV status through gossip in the community, and accordingly indicates that this would undermine what Sommerschild (1998) calls ‘closeness,’ that is relationships with a caregiver, family and the community.

Several of the children interviewed reiterated another point made by Nagler et al. (1995), that most children, once they have been told, will keep the secret as their parents and society have taught them to do:

‘It is difficult to talk with other people. It is difficult to talk to other people outside the family that my mother is infected’ (Study B, p. 28).

A mother who had disclosed to her children said:

‘I do not think they could describe their story to others. They are secret about their story…it is sensitive…’ (Study B, p. 40).

Children are socialised into the prevailing norms and would be aware of the need to keep certain information secret.

**Children’s feelings about a parent’s illness or death**

Children who had not been told about their parent’s HIV status reported feeling desperate, scared and helpless during their parent’s illness. A 12-year-old girl said:
'Sometimes I would get a feeling of fear and even could not eat food properly as I saw my father and grandmother get so sick. I would feel so sad. At times I didn’t have peace of mind and yet I could see my friends, for them they are happy and I am sad.’ (Study A, p. 32).

Another girl, age 17, described feeling hopeless: she could not imagine how she could survive without her parents. Feelings of helplessness and hopelessness indicate a lack of competence; children do not feel able or useful. So, not only are relationships compromised by cultural silence but competence may be undermined, with the result that children’s self-worth, confidence and self-esteem are diminished. Some children said that they hated themselves very much. Their situation is made worse when they compare their own unhappy lives to the happiness of their friends.

Most children realised the implications of their parents’ illness: their parents would soon die and they worried about their own future, realising that life would become more difficult without adult care. One 15-year-old girl said:

‘I started to worry and began to think about everything. I felt this was the beginning of our problems because even our own relatives did not even bother to come and visit my parents when they were sick. I thought that they were going to die and leave us alone and yet we don’t have support from other people. I thought that now who is going to take care of us at home if they die?’ (Study A, p. 35).

Children also worried about their material needs such as food, clothing and school fees. They acknowledged that their mother or father had always provided these things for them and they were aware that after their parent’s death, provision of their basic necessities could not be guaranteed. This generated anxiety and hopelessness in the children.

When children described their feelings concerning their parents’ deaths, some expressed anger and disappointment as well as fear and helplessness. Half the children in Study A said that their life was not worth living and they thought that the best thing for them would be to die and they actually thought of killing themselves. A 17-year-old boy from a child-headed household said:

‘When I lost my father, the way I felt was not good. I was disappointed, I felt small, humiliated, I was really disgusted. I felt this way because a big gap was created which will never be covered. Even right now as I speak that gap is there and no one is responsible to cover that gap’ (Study A, p. 37).

Cultural silence does not help children deal with loss and bereavement. And many children suffer multiple losses: when one parent becomes ill and dies there is a strong likelihood that the other parent will also die prematurely; they may subsequently lose other caregivers as well. Multiple losses increase isolation and further undermine a child’s sense of security. Cultural silence also ignores the experiences of children with HIV infection. A 12-year-old HIV-positive girl expressed the impact of multiple losses and illness on her life:

‘The time I really felt lonely was when my grandmother and uncle also died, because they were the people my father had left to look after me. And now when I think about them tears sometimes roll down my face [she wept]. Sometimes I find myself worried about my future since most of the time I stay at home while the other children go to school. I feel bad because I am left at home and feel lonely. I hate myself when the other children abuse me and don’t want to play with me because I am sick’ (Study A, p. 39).

This child is lonely; she is isolated from her peers, her family and her community. She has lived through the deaths of both her parents and the two caregivers chosen by her father. Alone, she worries about her future, feels bad and hates herself. Thus, cultural silence has undermined what little self-worth or resilience this child may have had. Her illness prevents her from going to school, which is an arena where she may have experienced competence.

**Disclosure**

Given the cultural taboos on adults speaking to children about death or sex, the decision of a parent to disclose their HIV status to their child is not taken lightly and is seldom done without some form of social support (such as a church group or the training given by NACWOLA). The reasons given by the HIV-positive mothers in the study by Bjørgo (2001) as to why they chose to disclose were wide-ranging. Some mothers wanted to tell their children themselves, rather than have them hear the news from the community gossip, as this mother explained:

‘I also learnt that when you tell something to your daughter she will not get it from other people. It is better for the girl to know it from you, because you also have the chance to explain. It is much better to tell the truth than let her go out in the street, playing with her friends, and hear — your mother has AIDS, your father died of AIDS — without knowing anything. The friends are bad, but if she knows, she will not hear it after them’ (Study B, p. 38).

Other mothers wanted to give their child a positive view of their father or to give them a sense of connectedness with their extended family:

‘Yes, I told him you have grandparents and they are still there, if you want to go to [your] aunt, she is still there. I tell him where he is coming from. Knowing where he is coming from is important’ (Study B, p. 34).

This sense of connectedness is part of the preparation for life after the death of the parent. This was another reason that HIV-positive mothers gave for wanting to disclose: they wanted their children to be prepared emotionally and in terms of care arrangements. One mother said:

‘When we are writing the memory book it is very important for us to write about family members... where my children can find help... I can show them where they can find the people who will be important for them, if they are defeated by the one I left for them, they can try someone else. I tell my daughter where she can find her aunt.... I tell her that if she is defeated by my side, they can try their father’s side. I write down where their aunt works and everything about her. And I show my daughter where she comes from.... One time will come when they have
no father, no mother... They can read the memory book, the page about their mother' (Study B, p. 33).

This mother has made care arrangements for the children in anticipation of her death but she has also given them alternatives by informing her daughter about her paternal relatives as well as her maternal ones. She has situated her daughter in the extended family network.

Mothers who have disclosed their status to their children described how extremely difficult it was for them to do so. They often delayed for some years after discovering their HIV status themselves and many described that they would not have been able to do so without the training given by NACWOLA. After having disclosed, they described experiencing a sense of personal freedom through having shared the burden of their HIV status and through knowing that their children had come to know the truth from them rather than through the gossip of neighbours.

The reaction of the children to a parent’s disclosure was often initially one of shock; many mothers and children described how the children had cried after first hearing the news. A 13-year-old boy said that when his mother told him she was HIV-positive:

‘I cried. I cried for I think two days. For two days, I was not speaking only crying…. After my mum told us...all the family cried. After that mum said — Do not worry...I will stay with you’ (Study B, p. 23).

Typically, the children then had many questions about where they would stay, who would look after them, who would pay their school fees. Openness allows time and space for these questions to be answered and a memory book provides a framework for writing down important information for the children. After that the parents and children often described their relationship as one where they were ‘free to talk,’ in other words, one of openness and closeness. One HIV-positive mother, when asked about how she discussed the future with her children, answered:

‘I tell them how I want them to behave, I talk about growing up, that I will respect them if they get the chance to get school fees, to get to work and to be a good and reasonable person..... I want them to look after each other. I want them to take their responsibility. I told to the youngest, the one at thirteen, that she has to take care of her older brothers and sisters. Do not think that just because you are last they are going to look after you...they are prepared for staying alone and take care of each other’ (Study B, p. 32).

After disclosure, greater openness from a mother about her status and illness enables a child to be very supportive. This has the added benefit of enhancing the child’s competence, and their sense of being able, useful and responsible. It also gives them a means to demonstrate their love. Most of the children in Bjørgo’s (2001) study were grateful that their own mother had disclosed her HIV status. They said that they grieved less after disclosure than before; they understood that their mother was not likely to die immediately and they had a better understanding of HIV/AIDS. It also enabled them to talk about what they thought would happen to them after their mother died.

However some children described how their mother’s illness and their concern for her made them keep silent rather than discuss problems with her. One boy explained: ‘...But I am afraid of the future, simply because I know we will face problems...but sometimes I try not to think about what will happen when my mother is not around. If I think it is going to be a problem, it is more difficult...so sometimes I try not to think about it. When school needs to be paid for and I am coming home...she is sick, what can I tell her? Sometimes I just have to keep quiet. I just sit down and think’ (Study B, p. 37).

Discussion

Limitations

The samples in each of the two studies were small; this feature may compromise anonymity and limit the validity of generalisations from the findings. However, all the interviews were done in-depth and had extensively explored children’s responses to their parent’s illness, disclosure (or silence), or death, as well as their own prospects for the future. The studies provided rich data that add insight and understanding to the phenomena of cultural silence and its impact on coping and resilience.

Analysis

The experiences of infected and affected children, parents and caregivers, described above, powerfully demonstrate how, on the one hand, cultural silence can undermine resilience, and on the other hand, disclosure or breaching cultural silence can enhance resilience. It must be noted that cases of disclosure that enhanced resilience occurred within a close relationship with one significant other. Such disclosure may be said to have breached cultural silence at a private level. The breaching of cultural silence at a public level needs to be handled with cultural sensitivity. Lie & Biswalo (1996a) note that the fear and anticipation of stigma prevent many people from sharing their HIV diagnosis and problems because they are afraid they will be rejected by the community; they wish to avoid the risk of hurting themselves, their children and their family. An enabling environment is necessary before cultural silence can be breached at a public level. In another paper, Lie & Biswalo (1995) describe community counselling as a multi-faceted approach that can arouse caring attitudes within the community, and so enable a person to disclose their HIV status publicly should they wish to do so. Changing attitudes through community counselling is an on-going process; successes at one stage facilitate the next stage and gradually lead to an enabling environment.

Parker & Aggleton (2003) comment that, to date, most interventions dealing with stigma (and the associated silence) have emphasised individualistic approaches such as increasing tolerance, empathy and altruism. Such interventions may not be appropriate in more collectivist societies where stigma and discrimination “are social and cultural phenomena linked to the actions of whole groups of people, and are not simply the consequences of individual behaviour” (Parker & Aggleton, 2003, p. 17). They stress that stigmatisation takes place in specific contexts of culture and power and is used to produce and reproduce social inequalities. Such an understanding of stigma and the
associated cultural silence require structural interventions beyond the scope of this paper.

Sommerschild’s (1998) model of resilience provides a useful framework for assessing the degree to which cultural silence (at a private level) impacts on resilience. When the conditions for coping (closeness and competence) are met, self-worth and resilience are boosted.

Closeness

Sommerschild (1998) defines closeness in terms of having at least one close relationship with a significant other, predictability and belongingness within the family, and social support from the community. Children who were not told about their parent’s illness and HIV status were denied closeness on all these levels. Their relationship with the sick parent was undermined by anxiety and fear because they knew something was wrong even though they had not been told about it. The lack of openness contributed to feelings of loneliness and isolation among children. HIV-positive women who had been infected by their husbands felt the same sense of loneliness and isolation when their husbands did not disclose their status to them, and so they were left to cope on their own in silence. Cultural silence also undermines closeness within the family. Sudden or unexpected illness disrupts routines and erodes predictability, both in the short and long term. Children expressed anxiety about who would look after them in the future, and fear about being left alone and not belonging to a family. Such fears were heightened by the fact that extended family members (uncles and aunts in particular) stopped visiting when the child’s parent was ill. The loss of routine and predictability intensifies insecurity. Frequently, when parents do not disclose their HIV status to their children, the children learn about it though gossip from neighbours. This isolates children further and reduces the possibility of social support from neighbours and the community. The two CBOs discussed in this study have done much to support and help orphaned and vulnerable children by providing an alternative form of closeness at the community level.

Disclosure can enhance closeness at all levels of relationships. Although the initial reaction of a child is likely to be one of shock and grief, disclosure allows for greater openness within the parent-child relationship. Though the situation may remain stressful after disclosure, children may subsequently ‘feel free’ to ask questions about anything that causes them anxiety, particularly who will care for them once their parent has died. While trust and closeness may be enhanced, in some instances (for example, when parents are very ill) children may refrain from asking questions or expressing their own anxiety out of respect for their parent’s condition.

Disclosure also allows time for the parent to arrange for an alternative caregiver and for a relationship to develop between the child and the new caregiver. The memory book system encourages parents to ‘connect’ children with their extended families, informing them about both paternal and maternal relatives. This has several positive effects: it gives the children a sense of where they come from as well as knowledge that they belong to a wider extended family, and it also provides alternatives should the initial care arrangements break down for any reason. The preparation and planning for care once the parent has died has the added advantage of increasing felt security and predictability for the children. While disclosure does not prevent gossip and stigma, it does enable the child to cope better because greater openness enables discussion and questions. It is interesting that mothers involved in the Memory Project were very concerned about protecting the reputation of their late husbands in the eyes of their children. Perhaps this reflects cultural values and the need for children to honour and respect their parents. Children also reported that their classmates were less likely to tease if they themselves were more open about their parent’s HIV status and illness. Witter (2004), examining the benefits of NACWOLA’s memory project, notes that many participants, having disclosed to their children, go on to speak publicly about HIV/AIDS and become regarded as community resource persons. The reduced stigma and improved attitudes towards HIV-affected households sometimes results in other benefits, such as increased flexibility over payment of school fees (Witter, 2004). In that case cultural silence has been breached at a public level.

Competence

Sommerschild (1998) describes competence in terms of being able, being of use, receiving and taking responsibility, demonstrating love, and encountering and handling adversity. Cultural silence reduces the opportunities for children to demonstrate competence, particularly in relation to their parent’s illness. Children who had not been told about their parent’s status described feeling desperate, scared and helpless during their parent’s illness; they felt unable to cope with the adversity and were overwhelmed by hopelessness. Their anxieties were often related to the provision for their future material needs: where would they get the food, clothing, shelter and school fees that they needed? They did not feel able or useful; nor did they experience a sense of responsibility, and their isolation and loneliness prevented them from demonstrating love.

Children in Uganda are expected to help with household chores, to run errands and take responsibility for younger children — thus accomplishing such tasks will convey some sense of competence. However, where disclosure has occurred children have additional opportunities for demonstrating competence; they are able to openly express their love and concern for their parents during bouts of illness as well as show their capability to help and care for them. Instead of feeling hopeless and helpless they perceive themselves as proficient and helpful. Witter (2004) notes that parents involved in a memory book project have reported significant improvements in communications and relationships with their children.

Conclusions

Sommerschild’s (1998) model of resilience based on closeness and competence as conditions for coping provides a useful framework for assessing the impact of cultural silence on the resilience of children orphaned by AIDS. Cultural silence, founded on deep-seated taboos concerning adults talking to children about sex and death, seems to be an added risk factor, increasing the vulnerability
of children who are without parents. Disclosure and openness, on the other hand, appear to act as protective factors, enhancing children's resilience by improving both closeness and competence.

Such insights have important implications for formulating policies. While specific interventions may target improving closeness and others may aim at increasing competence in order to promote resilience among children affected by HIV or AIDS, the underlying assumptions of cultural silence could undermine the effectiveness of an intervention. Dealing with cultural silence, combating stigma, and empowering HIV-positive parents to disclose their status to their children and openly address plans for their future are fundamental to interventions that seek to reduce vulnerability and enhance the resilience of orphaned children.

Notes
1 Theoretically there are no school fees, but there is still the cost of providing a uniform and writing materials.
2 Information obtained from AWOFS officials.
3 Information obtained from the NACWOLA website: www.designerswithoutborders.org/nacwola [Accessed 12 December 2005].
4 Cultural silence should not be confused with Paulo Freire’s (1972) ‘culture of silence’, which is more about a society’s sense of apathy resulting from internalising the message that it is backward, ignorant, incapable and lazy.
5 These concepts are also discussed in Daniel (2005a).
6 Quotations from Apila (2003) are referenced here as Study A, and those from Bjørgo (2001) as Study B.
7 For a detailed description of the methodology, see Apila (2003) and Bjørgo (2001).
8 Mothers who take part in the Memory Project complete a five-day course. During this time they learn about child development, appropriate ways to talk to children of different ages and at different levels of development about problems, illness and death. They learn about planning for the future of their children, how to write a will and about connecting the children with their extended family. They also receive training on how to help the children deal with the period after their parent's death (see Bjørgo, 2001).

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The authors — Marguerite Daniel currently holds a post-doctoral position at Bergen University. Her research interests include the impact on the community of programmes targeting vulnerable children, as well as the cultural responses to orphan care and the use of participatory research methods with vulnerable groups. Rune Bjørgo is a psychologist at Sørlandet Hospital, Kristiansand, Norway. After completing his master’s in psychology at the University of Bergen, he has spent the past three and a half years working with refugees and mentally ill people.

Hellen Apila completed her master’s in gender and development at the University of Bergen and is now working for ActionAid International in Kumi District, Uganda. As programme officer with responsibility for women's rights and empowerment, her work includes issues of girl-child education, HIV/AIDS, and adult education for women.

Gro Therese Lie is a social and community psychologist and professor of development-related health promotion at the Department of Education and Health Promotion and the Research Centre for Health Promotion (HEMIL), University of Bergen. She has worked for 20 years in joint Tanzanian-Norwegian research projects with the University of Dar es Salaam on HIV/AIDS-related challenges in selected Tanzanian communities. She has also worked in several other eastern, western and southern African countries. She has extensive experience with working with grassroots organisations in participatory evaluation and action research. Currently, she is the head of a multidisciplinary thematic research group working with ten African countries and the Middle East.

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