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## Risk and protective factors for psychological well-being of children orphaned by AIDS in Cape Town: a qualitative study of children and caregivers' perspectives

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### Abstract

By 2020, an estimated 2.3 million South African children will be orphaned by HIV/AIDS (Actuarial Society of South Africa, 2005), but little is known about risk and protective factors for their emotional and behavioural well-being. This qualitative study explores perspectives of affected families. Orphaned children ( $n = 60$ ), caregivers of orphaned children ( $n = 42$ ) and social care professionals ( $n = 20$ ) completed semi-structured interviews and focus groups. Participants were recruited from schools, shelters and welfare services. Findings from multiple sources indicate potential risk and protective factors in a range of dimensions, including bereavement, family functioning, social support, poverty, access to education and perceived stigma. Many factors reflected international literature on children experiencing similar stressors (e.g. non HIV/AIDS-related bereavement). However, this study also identified factors which may be specific to this group, notably stigma, abuse and peer factors. Current research is quantitatively testing associations between these identified factors and psychological outcomes.

This research is part of a collaborative project between Oxford University, Cape Town Child Welfare and the University of Cape Town.

When you don't have parents,  
no one to buy you clothes.  
Maybe you live with another family and  
they buy clothes for their own kids  
and you get none.

### Introduction

By 2005, an estimated 1.37 million South African children were maternal or double orphans, with 830,000 due to HIV/AIDS. Even with continued administration of the state Anti-Retroviral programme, numbers of orphaned children are predicted to reach 2.3 million by 2020 (Actuarial Society of South Africa, 2005).

The psychological well-being of children orphaned by HIV/AIDS is under-researched. Even less is known about factors in these children's lives which can affect their mental health. Psychological 'risk factors' are defined as variables which increase the likelihood of psychological difficulties, and

'protective factors' as variables which improve outcomes, despite environmental hazards (Rutter, 1979).

This study used qualitative methods to explore the perceptions of orphaned children, their caregivers, and care professionals about factors contributing to well-being in orphaned children. Results were used to inform programmes for affected children, and we are currently quantitatively testing associations between these perceived factors and psychological outcomes (sample  $n = 1025$ ).

### Risk and protective factors in mental health for orphaned children

Searches found very little available research on psychological risk and protective factors for orphaned children. Only one quantitative study focused specifically on this (Wild *et al.*, in press): Using standardized questionnaires, greater caregiver connection and greater neighbourhood and peer regulation were associated with less anxiety and depression. Other quantitative evidence identified factors such as household size (Atwine *et al.*, 2005), sibling separation (Nampanya-Serpell, 1998), parenting factors (Dutra *et al.*, 2000), and intervention effects (Rotheram-Borus *et al.*, 2004). Qualitative

research with affected families in South Africa has not focused on psychological health, but gives valuable indications for areas of focus. For examples, churches provide both support and stigma (Ferreira *et al.*, 2001), and poverty is a key cause of distress (ACCESS, 2002; Giese *et al.*, 2001).

Broader child mental health literature suggests factors such as genetic traits (O'Connor *et al.*, 2001) and abuse (Appleyard *et al.*, 2004). Certain factors may be particularly relevant to South Africa, such as affordability of school fees (Berry & Guthrie, 2003), violent crime and sexual abuse (Dawes, 2002), domestic (Heath & Kaminer, 2004) and community violence (Zissis *et al.*, 2000).

Orphans' experiences may overlap with those of other groups. Research with HIV+ adults identifies risks such as taboos on discussing death (Gosling *et al.*, 2004), and multiple bereavement (Sherr *et al.*, 1992). For example, many children report distress from the deaths of both parents and other family members (Richter *et al.*, 2004). Risks associated with childhood bereavement include witnessing traumatic death (Black & Harris-Hendricks, 1992) and financial instability (Stansfeld *et al.*, 2004). Witnessing, and caring for, a parent dying of AIDS may be particularly traumatic for a child (Richter *et al.*, 2004). Refugee children may share orphan experiences such as displacement (Fazel & Stein, 2003), multiple moves (Tousignant *et al.*, 1999) and bullying (Almqvist & Broburg, 1999). Many South African orphans are (formally or informally) fostered, and age at fosterhood and foster-family structure may affect placement stability (Minty, 1999). For orphaned streetchildren, the little available research identifies difficulties around lacking parental supervision (Richter & Van der Walt, 1996) and ambivalence around family contact (Vostanis, 2002).

However, a reliance on available evidence was considered insufficient. First, available quantitative studies only tested a limited number of researcher-identified factors. Second, reliance on research with groups whose experiences only partially overlap with those of orphans, risks inclusion of inappropriate factors, and third, there may be factors which are specific to urban African orphans, and have not yet been identified. In light of these concerns, we undertook a qualitative study to elicit the perceptions of orphans, their caregivers, and professionals, of factors contributing to emotional and behavioural well-being of orphaned children. The choice of a qualitative methodology was crucial in allowing the research to focus on participants' experienced meaning and human experience (Polkinghorne, 1989), and allowed a variety of data collection methods (Colaizzi, 1978) to understand more about a new phenomenon (Tesch, 1990).

## Methods

### Participants and eligibility

Participants included children orphaned by HIV/AIDS (60), caregivers of orphaned children (42), and care professionals (20). Children were recruited through three schools (50%), three streetchild-centres (27%), and, in order to access non school-attending children, through welfare services (23%). Caregivers were recruited through services in three areas. Participants lived in deprived (formal and informal) Cape Flats settlements, or in streetchild-centres. Professionals were interviewed at several welfare and community organizations.

Children were Black African, 43% male, aged 8–19 (mean 13.3, SD 2.7). Orphanhood was maternal (23%), paternal (27%), or double (20%). In some cases, one parent's whereabouts was unknown (30%). 61% lived with neither parent. Relationship to primary carer is shown in Figure 1. All streetchildren lived in centres. Of non-streetchildren, 61% lived in a concrete or brick home, 39% in a shack. 43% shared a room with 4+ people. 52% of homes had running water, 52% were waterproof. 42% of children reported going to bed hungry >1 night in the past week. Caregivers were Black African, aged 20–65, 90% female.

Orphanhood was defined here as children under 18, where one or both parents have died (UNAIDS *et al.*, 2002). However, we recognize that this definition may not reflect the importance of multiple caregiving arrangements, extended family, abandonment and wider familial losses due to HIV/AIDS in South Africa (Meintjies *et al.*, 2003).

### Procedures

Child participants were identified by teachers and social workers, and interviewed in schools, homes and welfare centres. Children were given a choice of worksheet-based semi-structured interviews,

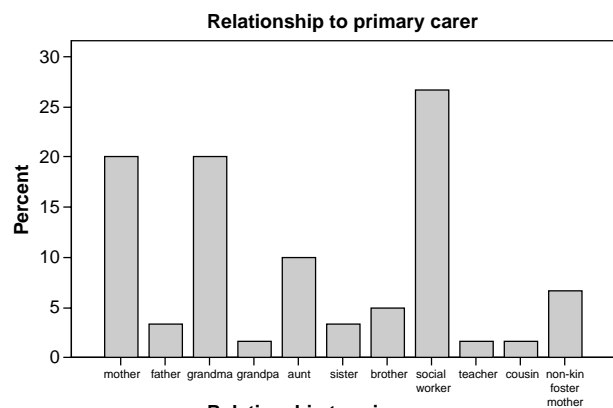


Figure 1. Relationship of child participants to their primary carer.

featuring popular cartoon characters<sup>1</sup>. Interviews explored factors which children perceived as affecting their happiness, sadness, anger and coping strategies. In order not to influence responses, bereavement was not mentioned. Children chose interviews in Xhosa (52%), English (15%), or dual-language (33%). Children opted to answer in relation to themselves (first person) or the cartoon character (third person), and chose to respond in writing, drawings, or verbally, independently or with interviewer assistance. These plural qualitative methods (Colaizzi, 1978) made the research more participatory (Strode & Barrett Grant, 2001), and allowed flexibility for a range of literacy levels.

Caregivers participated in Xhosa and English focus groups (averaging six participants), in welfare centres and homes. Questions followed children's interview schedule, but used a verbal instead of cartoon format. Individual interviews with professionals were open-ended discussions on risk and protective factors. All interviews and worksheets used open-ended questions and did not prompt responses. If a participant identified a particular factor (i.e. abuse) interviewers would enquire further. Data collected included worksheets and interview notes.

Cartoons, vignettes and drawings were found useful in other studies of HIV/AIDS-affected and low-literacy homeless children (ACCESS, 2002; Giese *et al.*, 2001; Herth, 1998; Strode & Barrett Grant, 2001; Thomas *et al.*, 2002). This study aimed for triangulation through multiple informants (Pendleton *et al.*, 2002) and data collection methods: interviews, focus groups and worksheets (Giese *et al.*, 2003; Kay *et al.*, 2003; Morrow, 2001)<sup>2</sup>.

Feedback to participants was prioritised (Herth, 1998). Participants were sent a thank-you letter, summary of findings (Kay *et al.*, 2003), and list of local resources for counselling etc.

### *Ethics*

Oxford University and Cape Town Child Welfare gave ethical approval. Interviewers were Xhosa and English-speaking social workers or auxiliaries, trained in working with HIV/AIDS-affected families. Participants were given refreshments and certificates.

Due to variable literacy levels, information and consent leaflets were also explained. For children, consent was also obtained from guardians, social workers or eldest siblings in Child-Headed Households. All data was treated as confidential, except information suggesting that children were at risk of significant harm (Alderson & Morrow, 2004).

Low rates of disclosure in South Africa (Anderson *et al.*, 2004) and high perceived stigma (Maughan Brown, 2004) mean many children are unaware of their parents' HIV status (Armistead *et al.*, 1999). Consequently, HIV/AIDS was not mentioned in recruitment or interviews. This approach follows other orphan psychological research in Sub-Saharan Africa (Makame *et al.*, 2002; Manuel, 2002; Poulter, 1996; Wild *et al.*, in press).

### *Analysis of qualitative data*

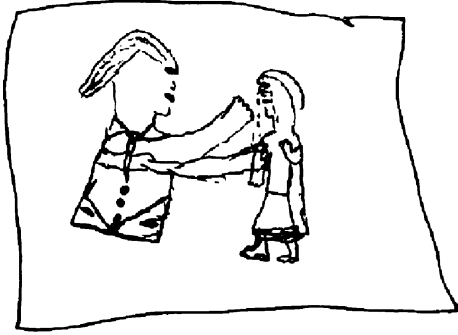
Using content analysis of written data (both qualitative and quantitative operations on the text; Weber, 1985), interviewer notes, participant writings and drawings were read through and significant statements extracted (Colaizzi, 1978). Meanings were formulated in order to produce clusters of themes. Themes were compared within and across categories to establish consistency (Glaser & Strauss, 1967) and referred back to original interviews in order to validate them (Polkinghorne, 1989). Priority was given to factors endorsed by high numbers of participants, and with high agreement between children, caregivers and professionals. In light of the phenomenological nature of our research questions, this study used a grounded theory approach (Glaser & Straus, 1967) to develop hypotheses. However, it is important to consider potential bias in analysis and selection of data for presentation. We aimed to identify 'factors' likely to be measurable and useful in intervention design. This may have caused bias against more intangible responses, such as general statements about positivity and hope. A peer audit was conducted on the final selection of themes, by 15 representatives from UNICEF, WHO and local NGOs.

### **Results**

Several key themes emerged from the data, and many factors were perceived as affecting both emotional and behavioural difficulties.

#### *Bereavement factors*

Children (n = 23), caregivers (n = 10) and professionals (n = 6) identified parental (particularly maternal) bereavement as a key risk for emotional/behavioural problems: 'When my mother goes out and never comes back'. Children felt that happiness would come from 'Having parents alive to take care of me' and, 'If I could see my dead parents again'. Multiple bereavement resulted in distress: 'When my friends, neighbours and classmates die', and survivor guilt 'She feels it is her fault her mother died'.



Picture 1. Being beaten (girl, 12).

Professionals highlighted anger and grief for teenage heads of Child-headed Households.

#### *Caregiving factors*

All participant groups stressed the importance (risk and protective) of the primary caregiver, for example, 'My sister does her best to look after us and we attend school regularly ... She washes our clothes when we're at school and allows us to play as children'. Children talked positively about 'being loved', attention, respect, 'being wanted', fun with caregivers and having boundaries; 'Being told if I've done wrong', as well as basic care 'When I am sick my grandmother takes me to hospital'. Five children described unhappiness from lacking any caregiver 'Having nobody to take care of me'.

Caregivers (n=41) perceived care as a crucial protective factor, including support, honesty, praise and closeness, help with homework, reading and stories, advice on education and attending school meetings. Professionals identified caregivers' mental health, social support, and access to anti-retrovirals as affecting children's well-being.

Harmful caregiving was highlighted by children (n=29), caregivers (n=24) and professionals (n=14). Risks particularly relevant to orphaned children included multiple moves, caregiver changes, and caregiver illness (for HIV+ or elderly caregivers). Others included family conflict, separation, domestic violence and alcohol abuse (common in these communities).

#### *Abuse*

Child abuse rates are high in Cape Flats communities (Dawes *et al.*, 2004; Heath & Kaminer, 2004) and featured in all groups' perceived risk factors for both emotional and behavioural problems (n=28). Twenty-three children identified shouting, and 14 described beatings with sticks or belts. Neglect included 'children locked in the shack whilst foster parent goes out'. Seven children identified distress caused by sexual abuse, including rape. Two chil-

dren witnessed abuse 'When I see a child my age being abused it makes me very sad'.

#### *New homes and 'a sense of belonging'*

Many participants were acutely aware of tensions associated with orphans' position as the non-biological child in the home: 'I am angry when the family is fighting and they refer to me as 'the orphan''. Caregivers described children's sense of abandonment and 'not belonging' within the family. Complexities emerged around disclosure to a child of their orphanhood: 'It is bad to deceive a child and tell them you're their mother when you're not ... now I know'. Caregivers and children also described positive factors: feeling accepted, wanted, and 'part of the family' (n=7). A child described his sister: 'She takes care of us, gives us the love we need as if we were her own children'.

Children were particularly unhappy when they felt discriminated against or different to other children in the home (n=10). This included unequal distribution of resources: 'When you're living with another family and they buy clothes for their children and not you', and were supported by adult data. Children also described isolation 'I want somewhere where people don't say "it's not your home"', and loneliness (n=4) 'I feel very alone in the world'.

#### *Contact with extended family*

Many participants saw lack of family contact as a risk. Children (n=6) described missing family, feeling separated, and 'Being sent far away'. Streetchildren were upset by others' family visits. Conversely, immediate and extended family contact was perceived as protective by professionals (n=3) and children (n=19). Children (n=8) identified family, often aunts, as a source of consolation.

#### *Poverty and access to services*

Almost all participants described poverty as a risk for emotional and behavioural distress. Primarily, lack of food/starvation was identified by children (n=53) caregivers (n=12) and professionals (n=10). Twelve children said 'enough food' would improve well-being. Concerns included insufficient food to take to school and going to school starving (n=3).

Specific poverty-related risk factors were homelessness (n=6), unemployment and no medical care. Housing problems included overcrowding, leaking or burned-down shacks (n=4), no toilets, electricity or water. Caregivers highlighted

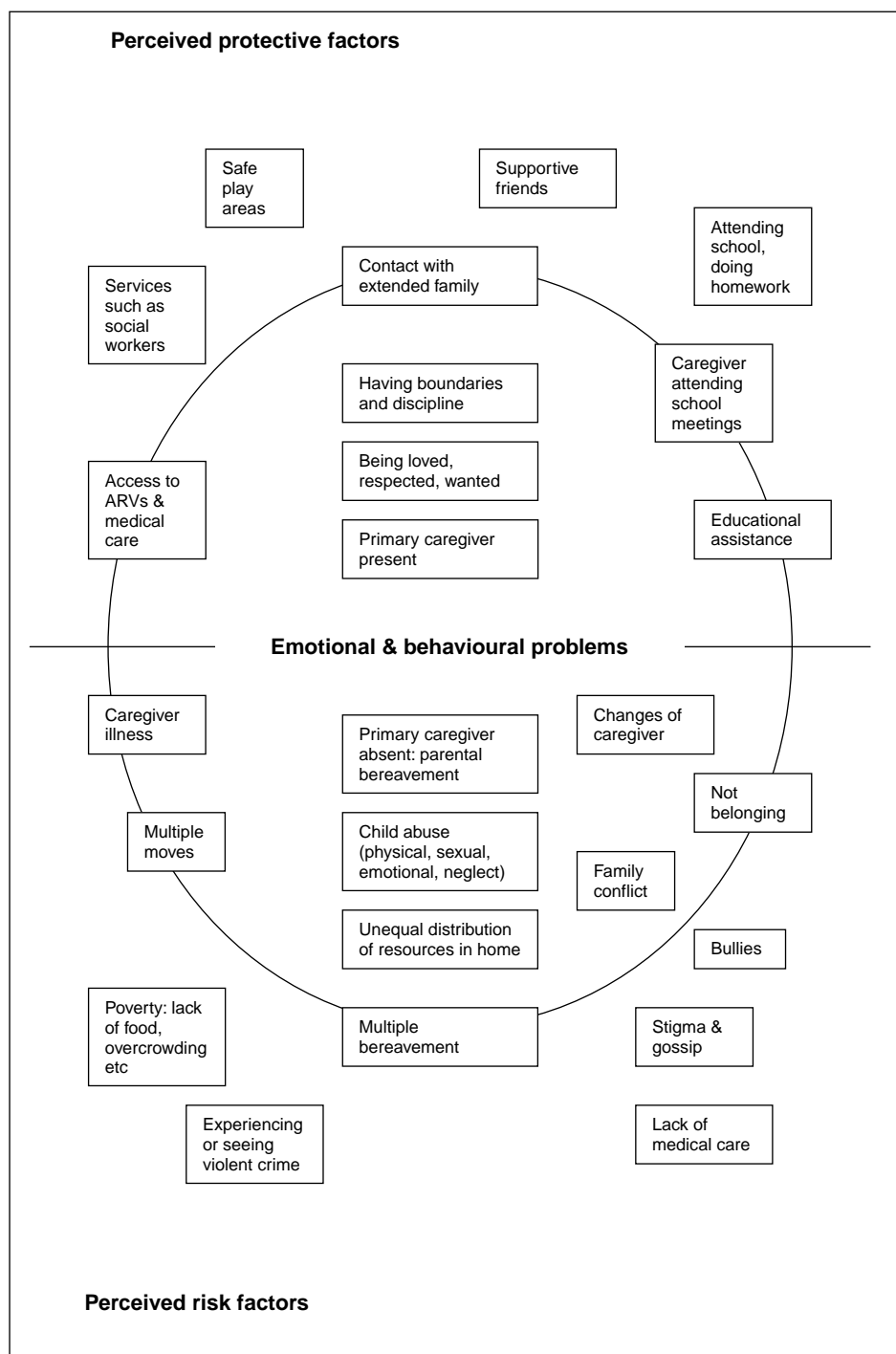


Figure 2. A graphic overview of findings.

difficulties around accessing social welfare grants, birth certificates, medical care, and social workers.

Caregivers and children identified orphans' sense of social exclusion, including inability to afford washing powder, haircare, a bath/shower and lack of birthday celebrations or activities with friends. Concerns around clothes (total  $n = 25$ ) included lack of school shoes and uniforms (required for school attendance), and winter clothes.

#### *School and peer factors*

Both school and friendships were important to children. Participants were distressed and angered by inability to afford school fees<sup>3</sup> ( $n = 10$ ), compulsory equipment and uniform, school transport and outings. These concerns over schooling costs support recent evidence of maternal bereavement negatively affecting educational access (Case &

Ardington, 2005). Where children did attend school, twenty-two identified it as a protective factor.

Children identified socializing as protective ( $n=20$ ), and friends as a source of comfort ( $n=29$ ). Lack of friends ( $n=9$ ), bullying ( $n=10$ ), teasing, fights ( $n=8$ ) and being beaten by friends ( $n=23$ ) were identified as risks: 'My friends make me sad because they bully me and swear me out and make fun of me. .. but I don't mind because they're my friends'. Heads of Child-Headed Households identified responsibilities restricting peer friendships. More generally, parentification and inability to 'be a child' were stressed.

#### *Physical safety and crime*

Children in townships are frequently exposed to crime, and 16 children were distressed or angered by muggings, robbery and assault. Others witnessed robberies, imprisonment and violence towards friends and family: 'beating someone or being beaten or my daddy being stabbed with a bottle'. Caregivers and children saw lack of safe play areas as encouraging behavioural problems. Six children were distressed by poor physical health, including stomach problems, headaches, and general illness 'My head's terrible and my body's sicked'.

#### *Stigma and gossip*

When some one is shouting at me  
and when people are gossiping about  
me or laugh at me or beat me up  
When people swear at my mother

Fourteen Children described stigma and gossip (although none mentioned HIV/AIDS). This included 'Gossiping about me behind my back', teasing, and being shouted at in public. Distress was caused by people 'Talking about my parents' ( $n=4$ ), and spreading rumours ( $n=6$ ). Notably, three children were distressed by verbal abuse towards surviving (possibly HIV+) parents.

#### *Positive activities*

All groups identified activities which improved well-being and provided comfort. These included sport ( $n=23$ ), playing ( $n=18$ ), TV ( $n=20$ ) and outings ( $n=11$ ), singing, music, dancing ( $n=10$ ) and reading ( $n=12$ ). Children gained comfort from

homework, diary-writing ( $n=5$ ), library visits, TV ( $n=13$ ), reading ( $n=6$ ), spending time alone ( $n=6$ ), sport ( $n=12$ ) and prayer/church ( $n=3$ ). Many stressed the importance of having a trusted confidante.

### **Discussion**

This study identified factors which orphaned children, their caregivers, and professionals perceived as affecting psychological well-being. Many factors are consistent with those found in literature on children experiencing other stressful life experiences such as homelessness or migration. However, some factors have not been previously identified, or have not been identified as having particular importance for this group. For example, perceived unequal treatment within new homes may be especially relevant to orphans in contexts of stigma and limited resources. Multiple bereavement and stressors on heads of Child-Headed Households reflect risks particularly (although not uniquely) relevant to AIDS orphanhood. Reported experience of gossip and teasing suggests a possible connection to HIV/AIDS-related stigma, supported by examples of gossiping and shouting at surviving parents.

Limitations include the sampling of only one Western Cape ethnic group (although this is the group most affected by HIV/AIDS). Study strengths include a good sample size and range of participants. In determining factors affecting child well-being, it is important to consider a range of sources of evidence, including those of service providers, caregivers and children themselves (Noble *et al.*, 2006).

This is the first qualitative study known to focus specifically on orphans' and their caregivers' perceptions of risk and protective factors for psychological well-being. The qualitative approach, through grounded theory, allowed us to develop hypotheses directly from the experiences of AIDS-affected families and from professionals, rather than use prior theories from research based on different stressors.

The findings of this study have contributed to the ongoing evaluation of Cape Town Child Welfare's 'Thembalabantwana' project for orphaned and affected children. They also contribute to the growing body of research in which AIDS-affected families provide input into intervention design.

Whilst a qualitative approach was important in allowing for participant-led identification of needs (and produced a high level of corroboration between participants on a number of factors), there is still potential to test identified factors in future research, both qualitative and quantitative. Larger-scale studies would allow exploration of findings in a wider geographical area, and with larger samples of AIDS-affected sub-groups (such as

Child-Headed Households). The use of positivistic, experimental methods to complement descriptive phenomenological methods allows for increased validation of findings (Valle *et al.*, 1989).

Whilst this study indicates participant-perceived stressors and protective factors, we also need to explore the effects of factors on prevalence of psychological difficulties such as depression. We need to distinguish which factors are specific to HIV/AIDS orphanhood, or to poverty more generally. It is only with further research that we can address factors affecting the psychological well-being of orphaned children.

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### Notes

- 1 Worksheets were available as 'Bart Simpson' and 'Lisa Simpson' (re-named Buntu and Lindiwe respectively) or 'Dragon-Ball-Z': the current cartoon craze for children in Cape Town.
- 2 Copies of worksheets and interview schedules, in Xhosa and English, are available on request: lucie.cluver@socres.ox.ac.uk
- 3 Schools in South Africa are legally required to accept fostered learners who cannot afford fees, but lack of state subsidy for non-fee paying learners can result in these children being refused school admission.

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