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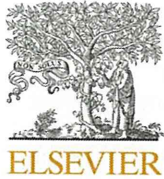

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Sibling caregiving among children orphaned by AIDS: Synthesis of recent studies for policy implications☆

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ABSTRACT

Objective: The HIV/AIDS epidemic has increased the number of orphans who have to care for their younger siblings. However, their caregiving practices are poorly reported. This review aimed to explore and accumulate available evidences on sibling caregiving among children orphaned by AIDS.

Methods: We conducted a systematic review of sibling caregiving among AIDS orphans in developing countries and identified 25 relevant articles. We analysed the compiled literature and extracted information on the prevalence of sibling caregiving, the framework of sibling caregiving, factors influencing caregiving, and the impact of sibling caregiving on caregivers and those cared for.

Results: Sibling caregiving, which includes economic, physical, psychological, and educational care, was influenced by children's, familial, community, and policy factors. Unlike sibling caregiving that occurs under adequate adult supervision, sibling caregiving among AIDS orphans negatively impacts both the sibling caregivers and the cared for. However, the lack of studies about such sibling caregiving had prevented measurement of the level of burden and impact of sibling caregiving on orphans.

Conclusions: Policy makers need to be aware that older children caring for younger siblings risk physical and psychological ill health and information must be collected so that measures can be developed to mitigate this burden on orphans.

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1. Introduction

The HIV/AIDS epidemic has caused a considerable increase in mortality among people of reproductive age [1]. As a consequence, more than 15 million children are estimated to have lost one or both parents because of AIDS [2,3].

National-level data on the prevalence of orphans affected by AIDS are available from Demographic and Health Surveys (DHS) and AIDS Indicator Surveys (AIS) (available at Measure DHS http://www.measuredhs.com/start.cfm). According to these data, the prevalence of paternal, maternal, and double orphans ranges from 2.1% to 17.7%, 0.5% to 3.8%, and <0.1% to 6.3%, respectively. Thus, in some countries, 1 in 5 children is orphaned by AIDS.

Traditionally, children orphaned by AIDS are placed with relatives, usually grandparents or aunts and uncles [1,4,5]. However, the rapid increase in orphans has overburdened the extended family network, leading to the emergence of child-headed households [6,7]. Child-headed households are more likely to have economic constraints [8,9]; have poor accommodation [10]; be disadvantaged in education [11,12]; and have physical [13], nutritional [14], and psychological [15,16] problems.

However, these disadvantages may not be equally distributed among orphaned children. The emergence of

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child-headed households suggests that the burden of caring for brothers and sisters falls on older siblings. In developing countries, sibling care is a common practice not limited to orphans [17]. However, in the case of AIDS orphans, older siblings care for younger siblings without supervision or support from adults.

Older siblings with HIV-affected parents assume the caregiver's role much before parental demise. As the parents develop AIDS symptoms and become too weak to work or care for their children, older siblings usually assume the parental role [18]. Older siblings often take on household chores, farming, caring for younger children, and nursing ill adults despite being in school themselves and in need of care. Baggaley and Needham [19] reported a case in which a child as young as 6-year old became the principal caregiver for a sick parent and younger siblings.

These caregiving children, who are often teenagers, need specific attention. They have burdensome responsibilities and stresses as compared to the children they care for despite being adolescents themselves. However, studies on the caregiving load of HIV/AIDS-affected families have focused on adult females and grandparents who adopt orphans, while the effects of sibling caregiving have not been well-documented.

This review aimed to explore and accumulate available evidence on sibling caregiving among children orphaned by AIDS and identify further research needs. The focus of this review was 4 questions:

1. To what extent is sibling caregiving prevalent among children orphaned by AIDS?
2. What kinds of care comprise sibling caregiving?
3. What factors affect the quality and quantity of sibling caregiving?
4. What are the impacts of sibling caregiving on caregivers and the cared for?

Guided by these review questions, we conducted a thematic synthesis of both qualitative and quantitative articles.

2. Materials and methods

2.1. *Operational definition of orphans, sibling caregiving, and sibling caregivers*

UNAIDS and UNICEF define an orphan as a child under 18 years of age whose mother (maternal orphan), father (paternal orphan), or both parents (double orphan) have died from any cause [3,20]. In our review, we followed this definition in principle. However, articles describing sibling caregiving were limited, and eventually, we included articles whose subjects included orphans up to 19-year old.

We defined 'sibling caregiving' as the act of siblings caring for their younger siblings. Sibling caregiving occurs not only among orphans but also among children living with both parents. It can be a culturally appropriate practice when it occurs under adult supervision. However, in the case of orphans who do not have adults supervising and advising them, the nature of the care, burden on the caregivers, and impact on their health differ from those under the normal practice of sibling caregiving. In our study, we limited our subjects to children orphaned by AIDS, and therefore, sibling caregiving was limited to caregiving that occurred under insufficient adult supervision.

The children being cared for were, in many cases, not defined but simply referred to as 'younger siblings'. We also defined the cared for as all children younger than the caregivers.

2.2. *Search strategy*

We followed the search strategy described by Petticrew and Roberts [21]. We conducted an electronic search of the literature from 2000 to date, using PubMed, MEDLINE, CINHAL PsycINFO and Academic Search Elite databases. Our search was completed on 25 September 2009. Search terms included 'AIDS' or 'HIV' and 'orphan', 'orphans', or 'orphaned' combined with 'siblings', 'younger' (for such phrases as 'younger sibling', 'younger children', and 'younger brothers and sisters'), 'child-headed household', and 'parentally bereaved'. To take into account the rapid changes in HIV/AIDS policies and treatment, we limited our search to articles published from 2000 to 2009.

The types of studies included in our review were original articles and reports from international agencies and NGOs that contain original qualitative or quantitative data on sibling caregiving by orphans. Case reports are also included because of the richness of the descriptions related to sibling caregiving. Exclusion criteria were reviews, commentaries, essays, opinions, letters, project reports, and physiological and psychological experiments. Articles that stated that children cared for their younger siblings but did not include concrete data or detailed descriptions were excluded. Studies conducted in developed countries were excluded because welfare systems are usually well-developed in these countries, and hence, the nature of sibling caregiving would differ between developing and developed countries.

We conducted an additional search 'by hand' by reviewing bibliographies of articles obtained through the electronic search. We also tried to locate 'gray' literatures such as conference proceedings, dissertations and theses by searching the following sources: COPAC, Dissertation Abstracts, and OpenSIGLE. Web pages of the United Nations and international NGOs were also searched in order to locate their reports. Thus, 250 potential studies were initially found.

Although there were many articles on children orphaned by AIDS, many did not include concrete data on sibling caregiving. The majority – 211 – described difficulties faced by and negative consequences for orphans of AIDS but did not relate these descriptions to sibling caregiving. Thirty-nine articles were eventually selected as articles containing information on sibling caregiving. We examined the content and quality of each study included in the synthesis, using the framework of Petticrew and Roberts [21] for surveys and an appraisal tool developed by Critical Appraisal Skills Programme (CASP) [22] for qualitative studies.

Sixteen articles were excluded: 6 articles did not have original data on sibling caregiving (e.g. narratives of

orphans), the sampling or recruiting methods of 3 articles were poorly described, and 3 articles duplicated results. In the case of qualitative studies, rigor of analysis was not found to be adequate for 2 articles and another 2 articles were published after 2000 but used data from early 1990.

Thus, 22 articles met our sampling criteria and were of adequate quality. Of the 22 articles, 4 were used to estimate sibling care rate; 15, to examine factors and impacts of sibling caregiving; and 3 for both. Of the 18 articles used to examine factors and impact of sibling caregiving, 13 employed qualitative methods or a mixture of qualitative and quantitative methods. Twenty-one studies were conducted in Africa and one study was from Asia. Because articles that estimated sibling care rate were limited in terms of study areas, we selected an additional 3 articles that used national- and provincial-level data even though their subjects were all types of orphans and were not limited to AIDS orphans. Thus, a total of 25 articles were included in the analysis.

2.3. Data analysis

Because no direct indicator for estimating the prevalence of sibling caregiving was available, we used sibling guardian rate. It counts households of orphans whose primary caregiver is a sibling and may include siblings older than 18 years. Child-headed household rate was excluded because sibling caregiving is not limited to 'children only households' but can also occur in households where children live with ill parents or dependent adults.

To explore factors and impacts related to sibling caregiving, a thematic synthesis was undertaken. There was no article whose primary focus was sibling caregiving. Therefore, we extracted descriptions regarding sibling caregiving from the articles selected for this review. Some articles were extremely descriptive, while others had just 1 descriptive paragraph. Each description was coded and then categorized into factors affecting the quality and quantity of sibling caregiving and its impact on caregivers and the cared for.

3. Results

3.1. Sibling care rate

Table 1 shows sibling guardian rates [5,9,23–30], which were used to estimate the prevalence of sibling caregiving. Sibling guardian rate ranged from <1% to 17% among sampled orphans or to <1% of surveyed households. However, the subjects differed among articles. Some included all types of orphans and others included only double orphans. The sibling guardian rates were 2–5 times higher for double orphans than single orphans.

3.2. Framework of sibling caregiving

Articles used for qualitative analysis of constructs, factors, and impacts of sibling caregiving are shown in Table 2 [5,9–13,31–41]. To answer the second question, 'what kinds of care comprise sibling caregiving', we tabulated the sibling caregiving described in the articles and developed a framework (Table 3). Sibling caregiving comprises 4 types of care: economic care, physical care, psychological care, and educational care.

Economic care included earning money for food, managing the household income and expenditure, and paying school fees for younger siblings. Physical care included daily activities such as doing household chores and caring for young siblings as well as emergency care of ill siblings. Psychological care was based on expressing love and care in the role of a sibling and probably in the role of a 'parent' responsible for the cared for. Educational care included training the cared for to assist in the daily care burden as well as preparing cared for siblings to be independent in the future.

A specific feature of sibling caregiving was its reciprocal nature. Although older siblings were the chief caregivers, younger siblings also shared responsibilities and occasionally played the role of caregiver towards older siblings, especially in the area of psychological care. The younger siblings would also 'earn and contribute to the household income' and 'talk about household issues, plan what to do and how to manage their household, and how to raise funds for schooling' along with the older sibling. The level of reciprocity depended on the relationship among siblings. Broken reciprocity was described as a sibling who 'was not interested in helping [older siblings]' or 'not cooperative'.

3.3. Factors related to sibling caregiving

Table 4 shows factors related to the quality and quantity of sibling caregiving. We found 12 related factors and categorized them areas as follows: children's factors, familial factors, community factors, and policy factors.

3.3.1. Children's factors

Children's factors included 'children's preference', 'caring ability of older siblings', and 'good sibling relationship'. Children chose to stay by themselves after their parents' deaths because they did not want to be separated, were afraid of maltreatment at a foster family, or were concerned about losing their inheritance rights to property and land. Advantages related to schooling, for example, geographic accessibility, were also factors that caused children to choose to take care of younger siblings despite the burden of caregiving [35]. Older siblings who acquired considerable experience in caring for their younger siblings before the death of their parents were better prepared to cope with the caregiving burden [39]. Siblings' good relationship was also a factor determining the quality and quantity of sibling caregiving; sibling caregiving increases resilience and coping capacity of orphans [11].

3.3.2. Familial factors

This category comprised 7 factors: 'parent's wish', 'parental training', 'relationship of family members', 'function of extended family network', 'incapacity or death of guardians', 'mistreatment at foster household', and 'isolation from relatives'

Mothers had an expectation to older siblings to help with caring for younger children when they got sick or foresaw their demise. Some parents wanted the children to stay

Table 1
Descriptive table of studies on sibling care rate.

No.	Author	Year	Country	Methods	Study area	Subjects	Sibling caregiver
1	Gilborn et al.	2001	Uganda	Quasi-experimental study (2 intervention 1 control)	Two districts, population not described	277 current guardians of orphans Age 5–17	5.3% (of sample orphans)
2	Nyambedha et al.	2003	Kenya	Cross-sectional	Sub-location of a district Population 79 833	243 orphans including 75 double orphans Age <18	All orphans 6.6% Double orphans 18.7% (of sample orphans) All aged 18 years and over
3	Masmas et al.	2004	Guinea-Bissau	Cross-sectional	The capital city and five most populous regions, total population not described, sampling using cohort population	Cluster sampling of women (100) Urban: 185 orphans, control 293 (2:1) Rural: 129 orphans, control 506 (4:1) Matched age, sex, area of residence Relatives of the sample interviewed	Before and after maternal death Urban: orphans 1.1 → 4.7% control 0.3 → 2.3% Rural: orphans 0.9 → 3.7% control 0.0 → 0.7% (of sample orphans)
4	Atwine et al.	2005	Uganda	Cross-sectional	A sub-county in a district, population 738,355	123 orphans due to AIDS 110 neighbor children with same age and gender Sampling method was not described Age 11–15	Sibling only household: Orphans 12.2% Non-orphans 0% (of sample orphans)
5	Sarker et al.	2005	Uganda	Cross-sectional	A parish, population not described, estimated orphans 4000	241 orphans and 278 non-orphans Age 12–59 months Cluster sampling	Non-orphans 0.3% Non-AIDS orphans 0.7% AIDS orphans 5% (of sample orphans)
6	Floyd et al.	2007	Malawi	Retrospective cohort	A district, population not described	134 orphans cared by HIV(+) index individuals and 662 orphans cared by HIV(−) matched index individuals Age <18	HIV(+) 8% HIV(−) 13% (of sample children living apart from both parents, not CHH)
7	Kumakech et al.	2009	Uganda	Cluster RCT	A municipality, population 1,089,051	Orphans due to AIDS aged 10–15: 298 Intervention 157, control 141	6.4–7.6% (of sample children)
8	Arnab et al.[a]	2006	Botswana	Cross-sectional	Nationwide	8380 households selected by stratified two-stage sampling Age <18	Total 8.6% Male 10.7% Female 7.6% (of sample orphans)
9	Saito et al.[a]	2007	Zimbabwe	Cross-sectional	21 districts, population not described	In selected districts: Children aged 5–17 years: 23,203 Orphans 8566 Non-orphans 14637 Children aged 6–59 months: 6925 Orphans 961 Non-orphans 5964	0.4% (of households)
10	Hill et al.[a]	2008	South Africa	Second data analysis	A province 11,000 households	28837 children aged <18	Household head[b] Non-orphan 0.4% Paternal orphan 3.3% Maternal orphan 2.8% Double orphan 15.7% School fees responsibility Non-orphan 0.7% Paternal orphan 2.2% Maternal orphan 3.3% Double orphan 14.5% Children's day-to-day care Non-orphan 1.6% Paternal orphan 2.6% Maternal orphan 4.6% Double orphan 8.6% (of sample children)

[a] These articles are showing national-level data of orphans, not limited to orphans due to AIDS.
[b] This sell indicates household head is a sibling of the cared child, school fees responsibility is on a sibling, and primary children's day-to-day caregiver is a sibling.

Table 2
Descriptive table of studies on factors and impacts of sibling caregiving.

No.	Author	Year	Country	Subjects	Methods
1	Social Impact Assessment and Policy Analysis Corporation	2000	Namibia	Interviews: 10 National-level key informants, 29 local key informants FGD: 36 caregivers FGDs, 31 orphans FGDs (107 orphans) Large group discussion: 13 meetings with Regional AIDS committee members Case study: 26	Qualitative and quantitative (key informant interviews, FGDs, large group discussions, case studies, statistical modeling using existing data)
2	Nyambedha et al.	2003	Kenya	243 orphans including 75 double orphans Age <18	Cross-sectional
3	Germann	2005	Zimbabwe	Questionnaire: 105 child-headed household head FGD: 83 CHHs, 34 volunteers and staff of OVC programs, 61 neighbors, friends and extended families, 21 childcare professionals and policy makers	Interview, FGD, bi-daily journal data collection, questionnaire
4	Hartell et al.	2005	South Africa	4 adolescents aged 15–18	Case study
5	Sarker et al.	2005	Uganda	241 orphans and 278 non-orphans Age 12–59 months Cluster sampling	Cross-sectional
6	Roalkvam	2005	Zimbabwe	A girl 9-year old	Case study
7	Yamba	2005	Zambia	A girl followed up from 9- to 21-year old	Anthropological case study
8	Arnab et al.	2006	Botswana	8380 households selected by stratified two-stage sampling Children aged <18: 737,241 Orphans 111,828 (15.2%)	Second data analysis
9	India HIV/AIDS alliance	2006	India	In-depth interview: CHHs Questionnaire: NGO directors) Interviewed: 29 CHHs (of 275), fostered children 6 (of 28), elders in CHHs 2, foster mothers 6 FGD: NGO staff 3, self-help group 3 Purposive sampling	Qualitative and quantitative (FGD: field staff of NGOs, CHHs, children under foster care, foster mothers, self-help groups)
10	Ruiz-Casares	2006	Namibia	Interview: 33 children in 30 child-headed households Survey: 33 children in child-headed households 163 non-orphans	Interview, group interview, observation, network mapping, survey
11	Wood et al.	2006	Zimbabwe	18 households (households in which breadwinner was chronically ill; a child–young person-headed household; an orphan has been fostered)	Qualitative (case study, semi-structured interview)
12	Abebe et al.	2007	Ethiopia	Field work: rural and urban orphans and families Interview: 42 orphans aged 8–17 y 18 household heads of orphans 12 social workers FGD: 8 orphans, 6 community leaders	Qualitative (observation, In-depth interview, FGD)
13	Cluver et al.	2007	South Africa	Children orphaned aged 8–19 by HIV/AIDS: 60 Caregivers of orphaned children: 42 Care professionals: 20	Children: Interview (answering in writing, drawing or verbally) Caregivers: FGD individual interview: care professional FGD
14	Landry et al.	2007	Kenya	Orphans aged 11–14 who had lost both parents within the previous 2 years: 31 Males 15, females 16 Their caregivers	
15	Birdthistle et al.	2008	Zimbabwe	Girls aged 15–19: 863 Blood samples of the girls: 839	Survey, HIV test
16	Kürzinger et al.	2008	Tanzania Burkina Faso	Orphans and non-orphans aged 6–18 y Tanzania 4931(no. of orphans is not provided) Burkina-Faso 4835 (orphans 777)	Survey
17	Schenk et al.	2008	Zambia	Wives of household heads: 1503 Children aged <18: 5009 FGD: male and female adult (>18 y) and youth (15–24 y)	Survey, in-depth interview, FGD
18	Withell B	2009	Uganda	Adolescents: 10	Interview

together by themselves and that the children, not relatives, inherit all properties. This determined the amount of help orphans could receive from relatives [11]. Some parents prepared children for future challenges [39]. Familial bond or conflict before parental decease affected the quality of sibling caregiving [11].

The function of the extended family network was a key factor in determining the quality and quantity of sibling caregiving. In rural areas, the extended family network functioned well and absorbed orphans into the network. However, even in societies with functioning extended family networks, sibling caregiving burden increased when HIV prevalence became high and the caregiving burden of orphans exceeded the capacity of the network. Extended family members might be reluctant to take in orphans if they already had their own children and foster children [34,35]. Or they might foster orphans but treat them harshly, resulting in older siblings deciding to care for younger siblings themselves [11].

Table 3
Framework of sibling caregiving by older siblings.

<Economic care>
Earn a living
Manage the household
Pay school fees
<Physical care>
Do household chores (cooking, sweeping, washing, fetching water)
Look after young siblings (feeding, bathing, getting ready for school)
Care for ill siblings/Seek treatment
<Psychological care>
Provide general emotional support
Help siblings cope with parental death
Show love/concern
<Educational care>
Train younger siblings in daily chores
Train younger siblings to help with farming/business

Note: Sibling caregiving can be reciprocated by younger siblings.

Table 4
Factors related to sibling caregiving.

Factors	Examples
<Children's factors>	
Children's preferences	Wanting to stay together
	Sense of responsibility
	Unwilling to be placed with relatives
	Wanting to continue living at their own residence in familiar surroundings
	Not wanting to be separated from siblings; siblings could be separated if siblings were fostered by different relatives
	Unwilling to relocate
	Wanting to secure inheritance rights to property and land
	Advantage for schooling
Caregiving ability of older siblings	Age of caregivers
	Skills developed and responsibilities managed before parents became terminally ill
	Learning child-care during caregiver's illness
Good sibling relationship	Children help and care for each other
<Familial factors>	
Parents' wish	Parents wanted siblings to stay together
Parental training	Parents prepared children for challenges
Relationship among family members	Pre-parental death and family conflict
	Some older siblings refused to care for younger siblings
Function of extended family network	Relatives' decision
	Relatives provide food and goods needed for daily use
	Extended families are reluctant to foster orphans
	Relatives respect children's decision to stay together
In capacity of guardians	Illness or death of a fostering relative
Mistreatment at fostered household	Relatives treat children badly
	Discriminatory treatment of children in the foster family
Isolation from relatives	Lack of support from relatives
	Familial problems before the death of parents
	Distance and lack of communication with relatives
	Separation from a surviving parent
	Migration
<Community factors>	
Child-care capacities of communities	Local initiatives providing support for food, schooling, and shelter
	Insufficient community support
	Need for support from churches
	Community's view about orphans
Services of health sector and NGOs	NGOs' operation of orphan support programs
	A clinic provided orphans with milk
	Community program works as a safety net
<Policy factors>	
Government policy and commitment	Government policy on orphans should be developed
	Policies must be implemented
	Rights should be protected

Table 5
Impact of sibling caregiving.

Impact	Examples
Care burden	Over work Responsible for household chores Multiple roles played by older sibling take (caregiver, bread earner, student) Responsibilities include caring for the sick and dependent adults
Economic responsibility	Struggling with poverty and hunger Playing the role of primary bread-winner Managing the household Coping with job disadvantage Having poor accommodation
Educational disadvantage	Dropout of school Late arrival to school Delay in school Sleepy/unable to concentrate Low school performance Resignation of future career
Psychological impact	Developing a sense of responsibility/achievement Strengthening of the relationship among siblings Feeling burdened and stressed Pitying oneself Having no time for fun/relaxation Dealing with younger siblings' grief in the midst of own sense of loss Dealing with challenge to identity caused by having to play parental role Feeling resentment at not receiving sufficient support from relatives and community
Social isolation	Losing school friends Restricted peer friendship
Compromised health and nutrition	Physical exhaustion and aches Malnutrition Inappropriate care of infants and ill siblings

Relatives were, of course, not always harsh. Relatives living near orphans might support them in their daily life [10,13]. Therefore, families that had migrated from rural areas to urban or mining or farming areas were especially vulnerable [30] because of isolation from relatives. Some relatives whom orphans were placed with treated the orphans with affection, caring and love. However, the foster parents, often grandparents, might become too weak or die. Yamba [33] reported the case of a girl orphan with 2 younger brothers, who experienced 3 consecutive bereavements: her mother, her grandparents who cared for them after the maternal demise, and her uncle and aunt who accepted the girl and her brothers after the grandparents' death.

3.3.3. *Community factors*

Two factors were related with communities. They were 'child care capacities of communities' and 'services of health sector and NGOs'. How much a community supports orphans varied with the community's economic conditions and culture. Some communities had local initiatives for supporting orphans with food, schooling and shelters, although these services could be insufficient and sporadic [10]. In some communities, orphans performed various services in exchange for support from community members [35].

Teachers were a source of support, providing tangible aid (food, blankets, school fees, and uniforms). However, the authority structure interfered with the provision of support, and orphans did not always recognize teachers as resources [35].

Existing services of the health sector and NGOs were also an important factor. Health visitors or NGO staff could alleviate the caregiving burden of older siblings by providing material as well as psychological support. A study found that orphans' educational status was relatively equivalent to that of non-orphans. The authors attributed this observation to family-based or community-based programs that worked as safety nets [12]. However, often the services were not sufficient and represented a small fraction of the children's support network [35].

3.3.4. *Policy factors*

Government policy had a crucial effect on sibling caregiving. However, in many developing countries, statutory support for orphans is not well-established or not well-functioning. Communities recognized that their support was not sufficient and that government commitment is necessary [10].

3.4. *Impact of sibling caregiving*

Six areas of impact were identified in relation to sibling caregiving: 'care burden', 'economic responsibility', 'educational disadvantage', 'psychological impact', 'social isolation', and 'compromised health and nutrition' (Table 5).

3.4.1. Care burden

Caring for younger siblings and managing the household were the responsibilities of the older siblings. They played multiple roles and were overworked. One article described the case of a 13-year-old boy [34] who went to school in the mornings, came home and cared for his 2 siblings, and then worked at a shop in the evenings. Sibling caregiving was especially challenging at first, but eventually, the older siblings got used to it and learnt to manage their various duties [5].

The caregiving burden involved caring for not only younger siblings but also ill parents and dependent adults such as debilitated grandparents or disabled members of the family. A girl whose mother was sick with AIDS cared for her dying mother and 2 younger siblings while working to support the entire household [11].

3.4.2. Economic responsibility

This was one of the most frequently reported impacts. Many older children had to work to supplement the income of the household [9–11,34,35,38,41]. They had to 'put food on the table [10]' and pay school fees of younger siblings. They also ran the household. They might discuss with younger siblings how to use the household income [11]. Some orphans did menial work or odd jobs, which are lowest on the earnings ladder [9]. Although the caregiving siblings worked hard, they often struggled with poverty and shortage of food [35].

3.4.3. Educational disadvantage

This was another frequently reported impact. One of the immediate impacts of AIDS on older siblings was that they had to dropout from school [10–12,31,35,38,41]. When children's caring responsibility increased, they were too tired or too busy to regularly attend school, leading to tardiness and poor academic performance [12]. They would arrive late to school because they had to first take care of and prepare younger siblings for school. Even though the caregiving siblings attended school, they were exhausted and could not concentrate [34]. Eventually, the caregiving siblings had to drop out of school and relinquish the possibility of a future career [33].

However, Kürzinger reported that after controlling for confounders, orphans' school attendance was relatively equivalent to that of non-orphans, suggesting that when family-based and community-based programs are well-functioning, they work as a safety net for orphans [12].

3.4.4. Psychological impact

Psychological impacts of sibling caregiving could be both positive and negative. On the positive side, older siblings developed a sense of responsibility and when they recognized that they were successfully managing the household and caring for younger siblings, they developed a sense of achievement [34,35]. Siblings' relationship was strengthened when siblings helped each other run the household and discussed such matters together [34,35] and when younger siblings appreciated the effort of the older siblings [37].

However, negative impacts were also reported. Older siblings were emotionally burdened and stressed [34,36]. Some caregivers felt unhappy and pitied themselves [34]. They were too busy and had almost no time for fun [35].

Wood [36] pointed out that 'older siblings often had particularly acute emotional burdens, having to deal with the grief of their younger siblings as well as with their own sense of loss'. Some concealed maternal death and told younger siblings that the mother was away on a journey [40].

When older siblings are forced to play the role of a 'parent' and can no longer play the role of a 'child', their identity might be challenged as they continue to develop [35,37]. Some orphans resented society because they felt that society did not provide them with adequate support [10].

3.4.5. Social isolation

Sibling caregivers risked social isolation. Because the caregivers dropped out of school and were too busy with various responsibilities, they lost school friends, and peer friendships in the community were also restricted [11,37].

3.4.6. Compromised health and nutrition

Sibling caregiving could have negative impacts on the health and nutrition of children orphaned by AIDS. Because of their heavy workload, caregivers were physically exhausted. A study in India reported that one such caregiving boy came back home late at night utterly exhausted [34]. Malnutrition among orphans was also reported [41].

Sibling caregiving impacts not only the caregivers but also the cared for. Some older siblings expressed fear that they might not have enough knowledge and might not be able to provide appropriate care for infants and ill siblings [11,34]. A girl recalled the time when all her 3 siblings fell ill and she had to care for them [32]. Older siblings might not recognize initial symptoms of diseases or they might provide inappropriate food or care for younger siblings [35].

4. Discussion

This study reveals the extent of sibling caregiving among children orphaned by AIDS and describes the framework, related factors, and impacts of such care.

In this study, we estimated the prevalence of sibling caregiving under inadequate adult supervision to range from slightly <1% to slightly over 10%, depending on where the data were gathered. Double orphans were especially at risk of being forced to care for siblings.

The concept of sibling caregiving is not limited to physical and economic care. Psychological and educational care is also its important components. A specific feature of sibling caregiving is its reciprocal nature. Although older siblings were the primary caregivers, younger siblings provided the older siblings with emotional care and shared economic and physical caregiving responsibilities. This concept serves as a framework for further studies.

In this systematic review, we found that sibling caregiving among AIDS orphans had many negative consequences for both the caregivers and the cared for. In previous studies dealing with sibling caregiving among children with parents, many positive aspects of such caregiving were highlighted [42,43]. Sibling caregiving gives rise to feelings

of happiness and contentment among older siblings when performed under appropriate adult supervision. However, among orphans, the responsibility of caring for younger siblings is more than their capacity in the context of the caregivers' ages. Sibling caregivers rarely receive sufficient help and support from their relatives and community. The overwhelming burden of caring borne by older siblings leads to economic, educational, psychological, and social disadvantages, negatively impacting their health. These disadvantages often force older siblings to leave school, resulting in restricted peer friendship as well as the imposition of the role of 'a parent' despite their young age [37].

These negative impacts may not necessarily be the consequences of sibling caregiving itself; rather, they might result from the shortage of support for orphans. Some studies reported that school attendance, treatment-seeking behaviour, and nutritional status of orphans were almost equivalent to those of non-orphans when confounders were controlled for or where an extended family network was functioning [12,13]. Negative impacts of sibling caregiving can be reduced if community and administrative support supplements the role of the extended family network.

Although numerous studies on orphans and child-headed households of AIDS existed, we could not find any articles that focused on sibling caregiving. Articles that included descriptions of sibling caregiving were from a limited number of countries. Half were from 3 countries: Uganda, Zimbabwe, and South Africa. Many articles used qualitative methods, and there was no study that quantitatively measured the caregiving burden of orphan caregivers.

More systematic data collection on the burden of sibling caregiving is necessary. Including sibling caregiving in DHS and AIS will help identify problems associated with sibling caregiving, particularly since orphans are a nation-level public health concern. Further studies are needed in the following areas: (1) the impacts of sibling caregiving on the health of child caregivers as well as the cared for in different socio-cultural contexts of AIDS-affected countries, (2) indicators that can be used to measure the burden and impact of sibling caregiving on orphans, (3) effective model interventions that can reduce the burden of sibling caregiving, and (4) the impacts of sibling caregiving on children made vulnerable by parental AIDS.

Our study has several limitations. First, although we focused on AIDS orphans, it was difficult to know if the studied orphans' deceased parents were in fact serologically HIV(+). Some of the articles we selected studied included all orphans living in areas with high HIV prevalence. Our results may not be specific to orphans of AIDS, but they reflect the situation of orphans living under the shadow of HIV/AIDS. Second, as mentioned above, quantitative studies on this topic were limited, and most articles we extracted used qualitative methods to describe the lives of orphans. Such studies may focus more than required on the negative aspects of sibling caregiving. Third, although we did not intend to limit our search to studies conducted in Africa, most of the studies that fulfilled our sampling criteria were from Africa. Therefore, our results mainly reflect the situation in Africa.

5. Conclusions

Our review presented frameworks for the concept of sibling caregiving, its related factors, and its impacts on caregivers and those cared for. Sibling caregiving has negative consequences for orphans of AIDS. However, these negative impacts can be prevented with sufficient support. Policy makers should be aware that older children who care for younger siblings risk physical and psychological ill health. Hence, it is important to gather information about sibling caregiving and take measures to mitigate this burden on orphans.

Conflict of interest statement

None declared.

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