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## Adolescent mothers affected by HIV and their children: a scoping review of evidence and experiences from sub-Saharan Africa

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### Abstract

While adolescents have received increasing attention in the global HIV response and international strategies and commitments, adolescent mothers and their children remain largely overlooked in research, funding and, programming for health-related outcomes. We conducted an extensive scoping review of current evidence on the experiences of adolescent mothers affected by HIV and their children in this region. We included published literature and conference abstracts, complemented by consultations with key stakeholders, and a review of documents through grey literature searching. First, we summarise the experiences of adolescent mothers and their children related to HIV and key health and development indicators. The syndemic of early motherhood and HIV in sub-Saharan Africa increases the vulnerability of adolescent mothers and their children. We then highlight lessons from a series of promising programmes focused on supporting adolescent mothers through novel approaches. In sub-Saharan Africa, supporting adolescent mothers living in high HIV-risk communities is critical not only to eliminate HIV/AIDS, but also to attain the Sustainable Development Goals. While research on and programming for adolescent mothers and their children is growing, the complex needs for this vulnerable group remain unmet. We conclude with evidence gaps and programming priorities for adolescent mothers affected by HIV and their children.

### Keywords

adolescence; motherhood; HIV; children; sub-Saharan Africa

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## INTRODUCTION

Adolescent pregnancy and birth rates within sub-Saharan Africa are the highest in the world, and current overall prevalence of adolescent pregnancy in the region is 18.8% (95% CI: 16.7–20.9; Kassa, Arowojolu, Odukogbe, & Yalew, 2018). Furthermore, sub-Saharan Africa is experiencing a “youth bulge”, with the number of adolescents expected to reach 435 million by 2030 (United Nations, 2017). Despite prevention efforts, adolescent pregnancy rates in the region have increased within recent years (Williamson, 2013), with countries such as Madagascar, Malawi and Mozambique reporting that over 30% of adolescent girls have initiated childbearing before the age of 20 (UNDP, 2015). Although many pregnancies among 15- to 19-year-olds take place in the context of early marriage, more than half of adolescent pregnancies are estimated to be unplanned and unintended (Darroch, Woog, & Bankole, 2016).

Within sub-Saharan Africa, adolescent pregnancy and motherhood occurs in the context of high rates of HIV. Sub-Saharan Africa remains at the centre of the HIV epidemic and is home to more than 20 million people living with HIV – half of the global population of people living with HIV (UNAIDS, 2018). Globally, over 2 million adolescents are living with HIV, an almost 30% increase in the past decade (UNAIDS, 2019). Moreover, based on recent global estimates, as many as 8 million adolescents in the region are HIV-exposed uninfected (HEU): born to HIV-women and exposed in-utero to HIV infection but not infected themselves (UNAIDS, 2018). Many more adolescents remain classified as Orphans or Vulnerable Children (OVC): orphaned by HIV, living in a household with people living with HIV, or vulnerable to HIV or the impacts of HIV, such as poverty and poor access to services. Adolescent birth rates within HIV-endemic communities range from 30–208 per 1000 births, a rate higher on average than non-HIV endemic countries (UNDP, 2015).

Research from high-income countries suggests that there are significant problematic outcomes associated with adolescent motherhood, either as a direct result of young age, or indirectly, through mechanisms linked to poverty, interrupted education, lack of support, isolation, reduced educational and employment opportunities, and limited access to services. These factors affect both adolescent mothers as well as their children and pose challenges for reaching them through policies and programming. The syndemic of early motherhood and HIV (whether living with HIV, being HEU, living in a household with HIV, living in a high HIV-endemic community or household) may increase the vulnerability of adolescent mothers and their children, especially in resource-constrained settings. However, to our knowledge, no existing reviews have been conducted on the intersection of these two health burdens, though several articles have called for additional research on this topic (Callahan, Modi, Swanson, Ng’eno, & Broyles, 2017; Groves et al., 2018). Considering high rates of early motherhood and HIV incidence in sub-Saharan Africa, it is critical that we understand and respond to this intergenerational issue through evidence-based programming that recognises the complexities of the lived realities of adolescent mothers and their children. This review summarises what we know about the experiences, challenges and efforts to support adolescent mothers and their children living in HIV-affected communities in sub-Saharan Africa.

## METHODOLOGY

The aims of this review were to map the evidence on the experiences of adolescent mothers and their children, based on three sub-topics: (1) the effect of HIV on their health and well-being, (2) experiences across different life domains for both adolescent mothers and their children, and (3) existing programmatic efforts to support adolescent mothers and their children.

### Data sources and search strategy.

A scoping review was undertaken to address these aims in May-August 2019. We searched scientific databases (PubMed including Medline, Google Scholar), and conference abstract archives (International AIDS Society, AIDSImpact) to identify relevant literature and documents. We also hand-searched relevant organisational archives (World Health Organization [WHO], United Nations Children's Fund [UNICEF], United Nations Fund for Population Activities [UNFPA]), as well as reference lists of publications from our search results (including systematic reviews), to identify further evidence. Keywords used within searches included: pregnancy, birth, adolescent/adolescence, HIV/AIDS, and associated synonyms. No language restrictions were applied during title and abstract screening; however, during data extraction we restricted the results to English language studies only. We identified additional unpublished materials through a desk review of programmes that were relevant and ongoing at the time of the search. Using these ongoing programmes, as well as drawing upon our existing networks, we further identified and consulted with experts working in research and/or programming with adolescent mothers in sub-Saharan Africa.

### Inclusion criteria.

To identify relevant documents collected through the online searches, grey literature review, and consultations with experts, we used the following inclusion criteria: a) included data from adolescent mothers 10–19 years (not exclusively restricted) and their children, b) focused geographically in sub-Saharan Africa, c) including adolescent mothers affected by HIV either by living with HIV, being HEU, living in a household with HIV, or living in a HIV-endemic community or country. Given the dearth of research on this issue, a broad definition of adolescent mothers affected by HIV (see above) was used to bolster findings relating to adolescent mothers and their children.

### Data extraction.

Two authors (KJR and CL) reviewed all documents and extracted data about adolescent mothers and their children using a standardised form including the following information: authors, year, country, methodology, type of evidence, study population and size, whether and which child data was included, and main results. For consultation, which included in-person as well as online meetings and email correspondence, notes were taken to capture similar types of data about specific research and interventions.

### Data synthesis.

Findings are presented as a narrative synthesis. Emerging literature was coded and relevant themes were summarised through two conceptual frameworks. First, we summarised the

impact of HIV and adolescent mothers and their children in three ways: (a) how HIV affects adolescents, (b) how HIV affects adolescent mothers, and, (c) how maternal HIV infection impacts the children of adolescents. Second, we extracted key indicators for adolescent mothers and their children: physical health, mental health, cognitive health, education, socio-economic status, safety and violence, and caregiving experiences. This synthesis and theme generation was guided by key informant interviews and a review of ongoing programmatic resources for adolescent mothers and their children to provide a comprehensive overview of the state of the evidence and practice on adolescent mothers affected by HIV and their children in sub-Saharan Africa.

## RESULTS

Of the 10,337 results identified through databases (n=10,185), conference abstract archives (n=145), and hand-searching (n=11), title and abstract screening for keywords relating to the topic of interest was undertaken for all documents and 61 documents were identified for full-text review. Ultimately, 34 full-text documents were excluded due to lack of relevance, a lack of data from our geographical location, or not reporting on the age range of interest. In total, 27 peer-reviewed publications reported data on adolescent mothers (10–19 years) and their children that spoke to the domains of focus (see Table 1). Included studies reported qualitative and quantitative data on the experiences of adolescent mothers affected by HIV and their children from eight sub-Saharan African countries: South Africa was the most common country of focus (n=14 of 27), followed by Kenya (n=6). Other countries of study included Malawi (n=2), Tanzania (n=1), Botswana (n=1), Lesotho (n=1), and multi-country (n=2). Most included studies reported on quantitative data (n=18), seven reported qualitative data and two used a combination of methods. Expert consultations were completed with twenty individuals representing ten organisations/institutions chosen based on a mapping of organisations working in this field in sub-Saharan Africa. Through these consultations and review of unpublished documents, nine programmes were identified which focused directly on adolescent mothers affected by HIV in sub-Saharan Africa, none of which were available as peer-reviewed publications.

We present the results of the scoping review in three parts in line with the specified frameworks for data synthesis: (1) the impact of HIV on adolescents, adolescent mothers, and their children, (2) progress of adolescent mothers and their children along key indicators, and (3) promising programmes to support adolescent mothers and their children.

## ADOLESCENT MOTHERS LIVING WITH HIV AND THEIR CHILDREN – A SYNDOMIC OF VULNERABILITIES

Living in high HIV-endemic areas exposes adolescents to a continuum of HIV-related risks, which in turn has implications for adolescent pregnancy and motherhood. Included research suggests that amongst pregnant and parenting adolescents, additional challenges may emerge relating to HIV infection. Many adolescent mothers find out about their HIV status at the same time as their pregnancies are confirmed, often after their first trimester (Nuwagaba-Biribonwoha et al., 2018; Ronen et al., 2016), which may also be linked to delayed ART initiation for PMTCT. Two studies report that adolescent mothers living with

HIV have less antenatal and postnatal care engagement, and are less likely to access programming that has shown to be effective among older mothers (Orne-Gliemann et al., 2017; Ronen et al., 2016).

Pregnancy may be a time of elevated risk of HIV exposure: in a study from Lesotho, the rate of seroconversions among 200 adolescent mothers was significantly higher than that among 741 older women (2.19 per 100 person-years compared to 0.67 for adult women; Macheke et al., 2018). Younger girls (15 years and younger) who become pregnant have been found to be more likely to subsequently become infected with HIV (Christofides et al., 2014).

Unpublished data from NGO programming and case reports reveal the complexities of this syndemic. Formative research for the development of the Gates Foundation-supported ABCD programme (PATA, 2019), reveal high levels of stigma among adolescent mothers living with HIV in Uganda. Young mothers living with HIV in South Africa were often forced to leave their homes due to family shame after becoming pregnant; they sought out new relationships for socioeconomic stability after their child's father refused to support them, putting them at risk of rapid repeat pregnancy in precarious situations (Josephine, 2019). Stigma and fear of gender-based violence associated with HIV-status disclosure have also been found to result in marginalisation and discrimination. These experiences are further exacerbated by internalised stigma—relating to both HIV and adolescent pregnancy (Josephine, 2019; Paediatric Adolescent Treatment Africa (PATA), 2019).

In addition to managing their own HIV status, adolescent mothers living with HIV need to also account for the physical, emotional and cognitive development of their children. Vertical HIV-transmission rates among adolescent mothers are three times higher than in adult women (Ramraj et al., 2017). Research from Southern Africa suggests that adolescent mothers living with HIV have much lower rates of accessing and adhering to ART in PMTCT programmes (Geoffrey Fatti, Sheikh, Mothibi, & Eley, 2014; Horwood et al., 2013; Ramraj et al., 2017; Ronen et al., 2016).

## **HEALTH AND WELL-BEING OF ADOLESCENT MOTHERS AFFECTED BY HIV AND THEIR CHILDREN**

Included studies reported data on several domains of well-being for adolescent mothers and their children, with several considerable research gaps. Substantial evidence on the physical health – including sexual and reproductive health – of adolescent mothers, the socio-economic factors and outcomes of adolescent motherhood are summarised below. Evidence on safety, violence and caring for children of adolescent mothers was limited. No primary data from sub-Saharan Africa was available on the educational experiences, cognitive and mental health of adolescent mothers affected by HIV.

### **Physical health, including sexual and reproductive health**

Adolescent mothers are less likely to engage and be retained in health services, including antenatal care, HIV testing and adherence to ART and PMTCT (G Fatti et al., 2014; Luseno et al., 2019; Ronen et al., 2016). For adolescent mothers who are not living with HIV but

reside within endemic areas, HIV exposure and testing remain important for physical health. After giving birth, adolescent mothers are less likely to use post-partum contraception—leading to repeat pregnancy, often still in adolescence, which carries additional risks for child health and survival (Birungi, Obare, Kwaak, & Namwebya, 2011; Norton, Chandra-Mouli, & Lane, 2017). Repeat unintended pregnancy among adolescents living with HIV is more likely to result in poor birth outcomes (Obare, Kwaak, & Birungi, 2012; Toska, Sherr, Cluver, Zhou, & Mzantsi Wakho Team, 2018).

Evidence shows that initiating and retaining adolescent mothers on HIV care is more challenging than doing so with older mothers—and is associated with additional physical and mental health risks for both mothers and children. Lila et al. found that in Tanzania, some pregnant adolescents did not know about PMTCT and were only tested for HIV at their first visit to the clinic (Lila, 2017). In Kenya, Luseno et al. found that adolescents experienced specific risks due to issues around autonomy, consent, and emancipation surrounding their HIV test results and treatment options (Luseno et al., 2019). Estimating rates of access to PMTCT for adolescent mothers is difficult because very few countries in sub-Saharan Africa collect specific large-scale data on PMTCT for adolescent mothers.

### **Socio-economic status**

Socio-economic factors are key drivers of adolescent pregnancy, and adolescent pregnancy also has implications for socio-economic status of adolescent mothers and their children, with a strong intergenerational effect. Studies across sub-Saharan Africa have investigated numerous socio-economic predictors of adolescent pregnancy: these include socio-economic status (SES), community-level poverty, low household income, and poor economic opportunities (Kaphagawani & Kalipeni, 2017; Mchunu, Peltzer, Tutshana, & Seutlwadi, 2012; Odimegwu & Mkwanzani, 2016). Once adolescents become mothers; they are more likely to have lower SES and reduced career prospects (Macleod, 2002), even after controlling for pre-existing social, economic, and health problems.

Lower SES may also affect adolescent mothers' ability to provide nutrients for their child's healthy development. Adolescent mothers, including those living with HIV, report conflicting sources of information about breastfeeding, in particular, whether to take breastfeeding advice from home or clinic (Jama et al., 2018). Adolescent pregnancy has been found to be associated with low birth weight (Mombo-Ngoma et al., 2016), which is linked to delayed development and growth milestones.

### **Safety and violence exposure**

A lack of social and psychosocial support has been reported as a barrier for engagement with PMTCT services (Carbone et al., 2019), highlighting how social support intersects with multiple domains for adolescent mothers. Pregnant and parenting adolescents are at a greater risk of intimate partner violence (IPV) compared to their non-pregnant, non-parenting peers (Closson et al., 2019). Likewise, IPV is also a risk factor for adolescent pregnancy (Omor et al., 2018).

## Caregiving for children of adolescent mothers affected by HIV

Parenting within the context of poverty brings numerous additional challenges. Caregiving tasks can be challenging for mothers who are straddling being an adolescent—going to school, supporting with chores at home—with being a parent and taking care of themselves and their children (Le Roux et al., 2019).

## PROGRAMMES REACHING ADOLESCENT MOTHERS AFFECTED BY HIV AND THEIR CHILDREN

Although there is significant evidence about the physical, psychosocial, and socioeconomic challenges that adolescent mothers face, we found that there were very few interventions addressing the needs of these vulnerable young mothers and their children in sub-Saharan African settings. No peer-reviewed publications reported on findings from such programmes, though several preliminary findings were reported in conference oral or poster presentations.

Interventions that seek to improve retention in care and HIV outcomes have struggled to produce successful outcomes amongst younger mothers in particular. Uptake and repeat pregnancy prevention interventions have tried to replace the success of adult adherence clubs and peer support groups, but with limited success (Kossow et al., 2012; Orne-Gliemann et al., 2017). Emerging qualitative evidence on programming designed specifically for adolescent mothers is promising, although quantitative evidence is not yet available for these initiatives (Carbone et al., 2019; Kossow et al., 2012).

Through grey literature and expert consultations, we identified nine existing programmes in sub-Saharan Africa (See Table 2), which highlighted four key features for promising programmes:

- 1. Mentorship and peers** Almost all of the programmes identified were delivered through models centred around peer mentors. Programmes such as mothers2mothers, Africaid's Zvandiri, and Ask-Boost-Connect-Discuss provide women living with HIV to become mentors for adolescent mothers living with HIV. These programmes extend the reach of HIV and primary health services by working through mentor mothers and peer supporters to provide support to adolescent mothers living with HIV. Current and future programmes must acknowledge the need to appropriately remunerate mentor mothers and peer supporters.
- 2. Group-based programming** Many programmes identified provided support for adolescent mothers in group-based settings, though rates of participation were not always high (Groves et al., 2018). Low rates of engagement in group-based programmes highlight the need to reduce barriers to access for adolescent mothers, which are often different to the issues faced by older mothers. Two group-based programmes used mobile technologies to facilitate access to information and support.

3. **Combining adolescent mother support with early childhood development** was part of some community-based programmes, including the AIDSFree, Regional Psychosocial Support Initiative and Kisumu Medical and Education Trust-delivered programmes in Malawi and Kenya.
4. **Holistic approaches to support adolescent mothers to overcome adversities and thrive** were part of several programmes. These included involving caregivers and families, providing childcare, support for return to school, and economic strengthening opportunities.

## DISCUSSION

This review aimed to give an overview of the literature on HIV-affected adolescent mothers and their children in sub-Saharan Africa and identify promising programmes for this population. Overall, data that speaks to the distinct challenges faced by adolescent mothers and their children in sub-Saharan Africa, as specifically relates to HIV, is limited, and not well-distributed across the African continent. This review identified four salient themes emerging from the available literature, including physical health, socioeconomic factors, safety and violence (child marriage, IPV, social support), and caregiving. Themes related to mental health, cognitive health, and education were largely absent from this evidence—particularly in relation to adolescent mothers living with HIV. Across these domains, barriers to health, well-being, and thriving of adolescent mothers persist, and more attention must be paid to their specific needs and concerns both during pregnancy and after the birth of their children.

Our findings can be contextualised within the larger body of research on adolescence and HIV. Adolescents living with HIV face a complex set of physical and emotional health challenges (Hoare, 2016; Lowenthal et al., 2012; Sherr, Croome, Parra Castaneda, Bradshaw, & Herrero Romero, 2014), and generally experience poorer treatment outcomes related to antiretroviral (ART) adherence, retention in care, and mortality (Dyer, Campeau, Toska, Hodes, & Cluver, 2019; Kariminia et al., 2018; Koech et al., 2014; Lamb et al., 2014). Once on ART, adolescents living with HIV report similar rates of sexual activity and pregnancy to their uninfected peers (Toska et al., 2017). As a result, although adolescents living with HIV are often discouraged from sexual relationships, many have relationships and become pregnant, and nearly all of these pregnancies are reported to be unintended (Toska et al., 2017, 2018). Moreover, although adolescent girls and young women may be at risk of HIV infection or living with HIV, their fertility desires and positive experiences of early parenthood are as important as their HIV prevention and treatment needs (Kane, Miedema, Dieleman, & Broerse, 2019; Mokgatle, Molapisi, & Madiba, 2017).

Published and grey literature confirms that adolescents living with HIV who then become pregnant face additional challenges such as regimen changes, the need to engage with PMTCT and additional burdens of stigma. For some, pregnancy may be the first time they learn of their HIV-positive status. Pregnancy is a time for elevated risk of contracting HIV, although the mechanisms of such risk need to be further explored. Younger mothers are more likely to experience post-birth dropout from lifelong ART (Clouse et al., 2013).



For the children of adolescents living with HIV, vertical transmission of HIV and infant testing remain central issues, particularly in relation to low engagement with PMTCT. Child development outcomes also remain an under-studied area. There are an additional set of emerging considerations relating to children of adolescent mothers living with HIV being exposed (in-utero, peri-partum, post-partum) to HIV and/or ART, but uninfected. HIV exposure has significant implications for child developmental outcomes, though quantitative data from children of adolescent mothers living with HIV is limited (Slogrove, Powis, & Cotton, 2019). Moreover, child health and well-being may be indirectly shaped by living within an HIV-affected household and the associated structural and socio-economic issues. As such, HIV infection may exacerbate health risks for adolescent mothers and their children.

Across core thematic areas, our review identified areas where evidence exists (physical health, socioeconomic factors) as well as where gaps remain for adolescent mothers affected by HIV. Despite the data available relating to the physical health of this population, no high-quality evidence from randomised controlled trials, or longitudinal or intervention studies, were identified. Adolescent mothers, who are at greater risk of postpartum complications and maternal mortality than older mothers (Grønvik & Sandøy, 2018). should be prioritised in future research. Furthermore, socio-economic factors are particularly pertinent to this group. Meta-analysis data from sub-Saharan Africa has identified numerous socio-economic risks that influence rates of adolescent pregnancy (Kassa et al., 2018). Adolescent mothers are at further risk of stigma, exclusion, and discrimination, perpetuating the cycle of poverty for themselves and their children (Wodon et al., 2017), and those living with HIV may be even more vulnerable.

Our review did not identify any primary studies in sub-Saharan Africa related to mental health, cognitive health, or educational outcomes of adolescent mothers affected by HIV. Globally, poor mental health has been found to be associated with adolescent pregnancy (Hodgkinson, Beers, Southammakosane, & Lewin, 2014; LePlatte, Rosenblum, Stanton, Miller, & Muzik, 2012; McCracken & Loveless, 2014; Mitsuhiro, Chalem, Moraes Barros, Guinsburg, & Laranjeira, 2009), although a systematic review showed mixed results of the impact of adolescent pregnancy on long-term mental health (Xavier, Benoit, & Brown, 2018). Many adolescents affected by HIV face mental health challenges related to family grief and HIV stigma-by-association, which are also key issues for parenting adolescents (Amzel et al., 2013). For adolescents living with HIV, both vertically and horizontally infected, internalised stigma and concerns surrounding disclosure to partners and loved ones are key concerns (Pantelic, Boyes, Cluver, & Meinck, 2017).

HIV-associated and neurocognitive disorders, as well as wider cognitive issues, have been found to be associated with HIV exposure and infection among children and adolescents (Kerr et al., 2014; Smith et al., 2013; The Lancet, 2013). Cognitive challenges have been associated with increased school absenteeism and delayed grade progression among adolescents living with HIV (Toska, Cluver, et al., 2019). While there is not data relating to adolescent mothers specifically in the literature, such cognitive issues should remain a consideration for this group and their children and remain a priority for research (Slogrove et al., 2019).

Lastly, adolescent pregnancy, as a visible and physical marker of early sexual activity, may make school-going adolescent mothers targets of stigma and discrimination through policies, laws and regulations, and from peers and teachers (Human Rights Watch, 2016a; UNESCO, 2017). This discrimination may take the form of expulsion once the pregnancy is confirmed (Human Rights Watch, 2016b), or mandatory tests or physical exams that are involuntary and degrading (Onyeka, Miettola, Ilika, & Vaskilampi, 2011).

Our additional review of nine programmes targeting adolescent mothers and their children found promising results, however evidence-based, scalable, and cost-effective programmatic responses for adolescent girls and young women living with HIV are still limited, particularly in resource-constrained settings. Pregnancy and motherhood remain largely absent from higher-level conversations around adolescents living with HIV, with approaches instead centred around denialism of their sexual practices, fertility desires, and relationships, and focusing primarily on prohibitions: don't forget your pills, don't tell anyone your status (to protect yourself), and don't have sex (Mackworth-Young et al., 2017). As a result, adolescent mothers living with HIV may be at risk of repeated, poorly-spaced pregnancies, which put them and their children at greater risk (Govender, Naidoo, & Taylor, 2019; Toska, Zhou, Laurenzi, & Cluver, 2019). UNAIDS has highlighted the need to make commitments specifically for reducing the number of new infections among adolescent girls and young women, who also report low rates of modern contraception uptake and high unmet demand (UNAIDS, 2019). Deepening our understanding of effective programmatic responses for this group are vital to improve outcomes on across both HIV and wider global agendas such as the SDGs.

### Implications of these findings

Effective policy and programming for adolescent mothers and their children requires adequate, accurate and timely data. Current data collection and routine surveillance does not adequately capture the overlap between young mothers and those living with HIV. How many of the young women living with, or affected by, HIV are also becoming mothers? Who are the adolescent mothers? Where do they live? What are their experiences of vulnerabilities that have resulted in adolescent motherhood? There are several reasons for why it is hard to collect this data.

**First, adolescent girls in some countries may become emancipated adults when they become mothers, and through motherhood, become included in data on adult women.**—Adolescent mothers living with HIV and their children are at the intersection of two vulnerabilities. They often report dual exclusion, stigma, and discrimination (Carbone et al., 2019). For adolescent mothers who are not HIV-infected but live in high-HIV contexts, this exclusion can also be keenly felt (Human Rights Watch, 2016a; UNESCO, 2017). This important population being overlooked in research, policy, funding and programming—and consequently being largely left out of the global HIV-focused response and maternal and child health work. Similarly, although the SDGs mark a shift towards adopting a more integrated and interdisciplinary set of priorities, HIV-affected adolescent mothers and their children are not explicitly recognised in the SDGs.

**Second, there are severe gaps in quantitative data on adolescent mothers affected by HIV and their children.**—HIV-affected adolescent mothers are near-

invisible in the large-scale quantitative data that would be necessary to highlight the scale of the issue: they are unable to be identified as a specific group, with specific needs, in the majority of international agency reports. This review has highlighted several areas of significant research gaps for adolescent mothers affected by HIV and their children.

Research with this group of interest is subject to several limitations. Adolescence, while defined by the WHO as the period of life between 10–19 years of age, is not delimited consistently in the literature and in larger-scale surveys, and may span 15–24 years of age. Further, many researchers choose not to engage children under 18 in studies due to more stringent ethical approval processes, so overall engagement of younger adolescents remains limited. Even where ethical procedures allow for recruitment, specific resources are often needed to support adolescent engagement, including specially trained researchers and acceptable measurement tools or interventions. Disaggregating data by 5-year age bands may be a strong first step to making this possible (Kingham, Shanaube, Toska, Cluver, & Bekker, 2018) so that data on 10–19 year-olds could be collated as needed.

Furthermore, research on longitudinal health outcomes for HEU adolescents and HIV-infected adolescents (either sexually-infected or vertically-infected), should be prioritized, with a specific lens on adolescent mothers and their children. Repeat pregnancies within adolescence are another area where more evidence is urgently needed, especially to inform policy and programming efforts. Lastly, within the literature, there is an assumption of negativity regarding adolescent pregnancy, and benefits and equalities are not necessarily articulated. Some evidence from high-income settings has shown that the experience of adolescent motherhood can also have positive mental health and emotional impacts, promoting self-esteem, self-worth and maturity (Seamark & Lings, 2004; Seibold, 2004; Spear & Lock, 2003). However, more research from sub-Saharan Africa is needed to highlight the complex experiences of young motherhood: negative, but also positive – as it is likely that effective interventions must build upon existing strengths and fueled by young parents’ aspirations. The broader literature suggests that the drivers of such negativity should be the target for provision, rather than a judgmental approach to age in isolation.

Adolescent fathers have been largely excluded from conversations around pregnancy prevention, early parenting support, and HIV. A recent systematic review examined the predictors and outcomes of adolescent fatherhood, but found no studies from Africa (Bamishigbin, Dunkel Schetter, & Stanton, 2019). Emerging evidence from South Africa in particular points to the importance of involving young men in research around HIV prevention, negotiating sexual situations, and preparing for childbearing and parenthood (Hodes & Gittings, 2019). As is the case with adolescent mothers, young men who are more vulnerable in certain ways—with lower education, and a greater number of sexual partners—have been found across contexts to be more likely to become young fathers than their peers (Amoo et al., 2018; C. O. Odimegwu, Amoo, & De Wet, 2018).

**Third, there remain substantive omissions in programming for this group. Adolescent mothers risk falling between the gaps in both adolescent HIV**

**prevention and adult-focused PMTCT support.**—Intergenerational socio-ecological considerations in providing HIV, sexual and reproductive health, and maternal health services are needed to ensure that adolescent mothers and their children do not fall through the gaps of being not-yet-adults, yet responsible for themselves and their children. Programming should account for adolescence as a special life stage. To that end, adolescent-focused services should engage caregivers and partners, who are both involved in, and central to, adolescent mothers' pregnancies and parenting experiences, where safe and feasible.

**Fourth, services key to the well-being of adolescent mothers and their children often lack integration.**—This fragmentation means that a population characterised by the intersection of multiple vulnerabilities can be both “prioritised” and at the same time excluded from necessary services. Hostile and punitive interactions between health providers and pregnant/parenting adolescents or adolescents living with HIV can also hinder their access to health services and products (Cluver et al., 2018; Josephine, 2019; Wood & Jewkes, 2006). Addressing the syndemic of adolescent motherhood and HIV requires that HIV programming—which primarily focuses on HIV prevention, treatment, and care amongst adolescents—is integrated with sexual and reproductive health and maternal and child health efforts, including family planning, antenatal and postnatal care, and early childhood development.

This paper presents a scoping review: while it is possible some literature may have been missed using the outlined search strategy, we believe the sensitivity of the search was enhanced by searching in references of relevant documents and the input of key informant interviews relating to the topic. Due to the limited number of documents on the topic of interest, documents that non-exclusively included the age group of interest (adolescence; 10–19 years) were included within extracted information to ensure a comprehensive overview. Additionally, the quality of evidence has not been assessed. However, to the authors' knowledge, this review presents the first summary of the current state of the evidence relating to HIV-affected adolescent mothers and their children.

Despite these limitations, this review highlights a vast gap in understanding of adolescent mothers with HIV and their young children. The research, where it exists, is often focused on a negative perspective of adolescent parenting, which detracts from the need to understand the drivers of specific outcomes and provisions which would counterbalance these. Although the data does suggest that many such pregnancies are unplanned, they are not always unwanted. Evidence is needed to inform relevant, acceptable solutions to meet the needs of these young women. Sector-based programming for adolescent mothers affected by HIV, including health, education, social development and employment is needed. Programming should also include early childhood development – focusing on nurturing care (WHO, 2018)– to support the needs of children of adolescent mothers. Integrating health services to increase early engagement and access to antenatal care services has the potential to bolster outcomes for children of adolescent mothers. Furthermore, although HIV has generated much stigma and discrimination, the needs of adolescent parents, especially those living with HIV, should be considered in through comprehensive approaches that focus on

long-term quality of life and the achievements of both generations: young parents and their children.

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**Table 1:**

Primary studies including pregnant adolescents/ adolescent mothers affected by HIV in sub-Saharan Africa

	<i>Authors, (year)</i>	<i>Country</i>	<i>Method</i>	<i>Description of sample</i>	<i>Child data included?</i>	<i>Key topics</i>
1	Birungi et al. (2011)	Kenya	Quantitative	506 adolescent mothers living with HIV	No	<ul style="list-style-type: none"> <li>• PMTCT/ART</li> <li>• Healthcare</li> </ul>
2	Carbone et al. (2019)	Malawi	Qualitative	Adolescent mothers living with HIV (n=72); disaggregated by those who had experience of programming (n=38) vs. those who had no experience of programming	No	<ul style="list-style-type: none"> <li>• PMTCT/ART</li> <li>• Healthcare engagement</li> <li>• Support services</li> </ul>
3	Christofides et al. (2014)	South Africa	Quantitative	1099 HIV-negative women (15–26 years), disaggregated by early adolescent pregnancy (15 years or younger), later adolescent pregnancy (16–19 years) and women who did not report an adolescent pregnancy	No	<ul style="list-style-type: none"> <li>• HIV incidence</li> <li>• Early pregnancy</li> <li>• Partner age disparity</li> </ul>
4	Closson et a. (2019)	South Africa	Quantitative	253 sexually-active women ages 16–24, not currently pregnant; reporting experiences of intimate partner violence and pregnancy between age 15–19	No	<ul style="list-style-type: none"> <li>• Adolescent pregnancy</li> <li>• Intimate partner violence victimization</li> <li>• Risk factors for HIV</li> </ul>
5	Fatti et al. (2014)	South Africa	Quantitative	956 HIV-positive pregnant women; included adolescents (19 and younger); young women (20–24) and older women (25+)	No	<ul style="list-style-type: none"> <li>• HIV status awareness</li> <li>• Healthcare/ANC</li> <li>• PMTCT</li> </ul>
6	Govender et al. (2018)	South Africa	Multi-method	326 adolescents, including pregnant/parenting adolescents	<ul style="list-style-type: none"> <li>• Birth outcomes</li> <li>• Low birthweight</li> <li>• APGAR scores</li> <li>• Gestational age</li> </ul>	<ul style="list-style-type: none"> <li>• Healthcare including antenatal care</li> <li>• Birth outcomes</li> <li>• support</li> <li>• Barriers to accessing antenatal care</li> </ul>

	<i>Authors, (year)</i>	<i>Country</i>	<i>Method</i>	<i>Description of sample</i>	<i>Child data included?</i>	<i>Key topics</i>
7	Hill et al. (2015)	South Africa	Qualitative	15 adolescent living with HIV and not living with HIV (14–17 years)	No	<ul style="list-style-type: none"> <li>Relationships</li> <li>Support</li> <li>Family</li> <li>Partners</li> </ul>
8	Horwood et al. (2013)	South Africa	Quantitative	19093 mothers (12–39 years) including 4485 adolescent mothers	No	<ul style="list-style-type: none"> <li>ART/PMTCT</li> <li>Healthcare</li> </ul>
9	Jama et al. (2018)	South Africa	Qualitative	30 pregnant participants recruited to the study; findings drawn from 10 adolescent mothers (15–19 years); monthly in-depth interviews were conducted with participating mothers for 6 months starting 2 weeks after delivery	No	<ul style="list-style-type: none"> <li>Breastfeeding</li> <li>Support</li> </ul>
10	Josephine (2019)	South Africa	Qualitative	10 adolescent mothers living with HIV	No	<ul style="list-style-type: none"> <li>Psychological challenges of pregnancy</li> <li>Economic challenges of pregnancy</li> </ul>
11	Kaphagawani & Kalipeni (2017)	Malawi	Quantitative	505 adolescent mothers	No	<ul style="list-style-type: none"> <li>Planned pregnancy</li> <li>Predictors of pregnancy</li> </ul>
12	Kossow et al. (2012)	Botswana	Qualitative	20 adolescent mothers living with HIV	No	<ul style="list-style-type: none"> <li>Support</li> <li>Education</li> <li>ART/PMTCT</li> </ul>
13	Kumar et al (2018)	Kenya	Qualitative	8 pregnant adolescents who screen positive for depression; 22 adolescent mothers (interviews and focus group discussions)	No	<ul style="list-style-type: none"> <li>Adolescent pregnancy and depression</li> </ul>
14	Le Roux et al. (2019)	South Africa	Quantitative	458 participants, adolescent (<18 years) vs. older mothers	<ul style="list-style-type: none"> <li>Child support grant receipt</li> <li>Breastfeeding</li> <li>Immunization receipt</li> <li>Low birth weight</li> </ul>	<ul style="list-style-type: none"> <li>Socioeconomic outcomes</li> <li>Caregiving</li> <li>Breastfeeding</li> <li>Education</li> <li>Child outcomes</li> </ul>

<i>Authors, (year)</i>	<i>Country</i>	<i>Method</i>	<i>Description of sample</i>	<i>Child data included?</i>	<i>Key topics</i>
				• Growth	
15 Lila et al. (2017)	Tanzania	Mixed methods	50 adolescent mothers (qualitative) paired with Tanzania DHS 2016 data	No	<ul style="list-style-type: none"> <li>• PMTCT</li> <li>• Healthcare</li> <li>• Risk factors for pregnancy</li> </ul>
16 Luseno et al. (2019)	Kenya	Qualitative	28 participant interviews, including 9 adolescents mothers living with HIV (aged 15–19 years), 4 family members and 15 HIV providers	No	<ul style="list-style-type: none"> <li>• Healthcare</li> <li>• ART/PMTCT</li> <li>• Disclosure</li> </ul>
17 Machezano et al. (2018)	Lesotho	Quantitative	HIV-negative pregnant women, assessed routinely from recruitment (antenatally) through 24 months post-birth; sub-sample analysed between ages 14–24	No	<ul style="list-style-type: none"> <li>• HIV incidence</li> <li>• Risk factors for HIV acquisition, including age</li> </ul>
18 Mchunu et al. (2012)	South Africa	Quantitative	3123 adolescents drawn from a population-based household survey	No	<ul style="list-style-type: none"> <li>• Prevalence of pregnancy/fatherhood</li> <li>• Planned pregnancy</li> <li>• Predictors of adolescent pregnancy</li> </ul>
19 Mombo-Ngoma (2016)	Benin, Gabon, Mozambique, Tanzania	Quantitative	4749 participants including adolescents (975; <19 years)	<ul style="list-style-type: none"> <li>• Birth outcomes</li> <li>• Birthweight</li> <li>• Preterm delivery</li> </ul>	<ul style="list-style-type: none"> <li>• Birth outcomes</li> </ul>
20 Nuwagaba-Biribonwoha et al. (2018)	Kenya, Tanzania, Uganda	Quantitative	Patients (10+) initiating ART at clinics, grouped by young adolescents (10–14); older adolescents (15–19) and general (20+); pregnancy initiation was measured as a correlate of lost-to-follow-up	No	<ul style="list-style-type: none"> <li>• ART/PMTCT</li> <li>• Healthcare</li> </ul>
21 Obare et al. (2012)	Kenya	Quantitative	797 female adolescents living with HIV (aged 15–19 years), of whom 394 had ever experienced pregnancy	<ul style="list-style-type: none"> <li>• Birth outcomes</li> </ul>	<ul style="list-style-type: none"> <li>• Repeat pregnancy</li> <li>• Birth outcomes</li> <li>• Contraception use</li> </ul>

	<i>Authors, (year)</i>	<i>Country</i>	<i>Method</i>	<i>Description of sample</i>	<i>Child data included?</i>	<i>Key topics</i>
22	Odimegwu et al. (2018)	South Africa	Quantitative	Lifestyle data from the Centre for Justice and Crime Prevention (2009) focusing on youth aged 12–22 years	No	<ul style="list-style-type: none"> <li>Father (young men) engagement in pregnancy</li> </ul>
23	Omoro et al. (2018)	Kenya	Quantitative	Demographic surveillance data; 1952 girls 13–19 years, of whom 454 had experienced pregnancy	No	<ul style="list-style-type: none"> <li>Incidence of pregnancy</li> </ul>
24	Ramraj et al (2017)	South Africa	Quantitative	4,814 adolescent (<20 years) and 25,453 (adult) mothers from three national representative, cross-sectional, facility-based surveys, conducted in 2020, 2011–2012, and 2012–2013	4–8 weeks infants	<ul style="list-style-type: none"> <li>Early MTCT rates</li> </ul>
25	Ronen et al. (2016)	Kenya	Quantitative	2521 mother-infant pairs attending maternal child health services including HIV-positive mothers and 278 adolescents (12.8%)	No	<ul style="list-style-type: none"> <li>Healthcare /ANC</li> <li>ART/PMTCT</li> </ul>
26	Stoner et al. (2019)	South Africa	Quantitative	2533 young women (13–20 years) not married or pregnant at baseline enrolled and attending high school grades 8–11	No	<ul style="list-style-type: none"> <li>School dropout</li> <li>Incidence of pregnancy</li> </ul>
27	Toska et a. (2018)	South Africa	Quantitative	563 HIV-positive adolescent girls, interviewed 18 months apart to identify incident pregnancy	<ul style="list-style-type: none"> <li>Knowledge of child's HIV status</li> </ul>	<ul style="list-style-type: none"> <li>Incidence of pregnancy</li> <li>Risk factors for pregnancy</li> </ul>

**Table 2:**

Summary of promising programmes to support adolescent mothers affected by HIV in sub-Saharan Africa

Intervention/ Programme name	Implementing partner	Country of implementation	Key populations	Delivery mode	Key outcomes
Ask-Boost-Connect-Discuss (ABCD)	Paediatric Adolescent Treatment Africa (PATA)	Malawi Tanzania Uganda Zambia	Adolescents and young women living with HIV who are pregnant or parenting; their children	Support groups facilitated by a trained peer using a mobile-based programme	Social support, mental health, linkage to services ( <i>feasibility and acceptability</i> )
Zvandiri Young Mentor Mothers	Africaid	Zimbabwe	Adolescents living with HIV, including those who become parents	Home- and clinic-based	Psychosocial support, support for disclosure, initiation onto ART, linkage to services
Community Model for Fostering Health and Wellbeing for Adolescent Mothers and their Children	Regional Psychosocial Support Forum (REPSI)	Malawi	Adolescents mothers including marginalized married girls and their children	Group-based sessions including a peer champion	Psychosocial support, infant care, improved health and hygiene, improved confidence, personal development, linkage to other opportunities
Jielimishe Uzazi na Afya (JUA)	AIDSFree, JSI	Kenya	Adolescent mothers, including some who were living with HIV, and key family and people in their networks	Home-visiting team	Better access to health and social services, including school re-entry and retention
Mentoring Adolescent Mothers At School (MAMAS)	Drexel University	South Africa	Adolescent mothers, including some who were living with HIV	Group-based sessions	Return to school ( <i>feasibility and acceptability</i> )
mothers2mothers	mothers2mothers	Malawi South Africa Uganda Zambia	Mothers living with HIV, including adolescents	Home- and clinic-based	Initiation onto ART, PMTCT, higher enrolment rates
Teen Mothers Support Groups	Botswana-Baylor Children's Clinical Centre for Excellence / Baylor University	Botswana	Adolescent mothers living with HIV	Group-based sessions	
Project Insaka		Zambia	Adolescent mothers	Group-based sessions delivered through open-source mobile technology	Engagement/ Participation in group-based sessions delivered through mobile phone technology
Sisterhood for Change, Changamsha Watoto	Kisumu Medical and Education Training (KMET)	Kenya	Adolescent mothers living with HIV and their children	Group-based sessions	Early child development, economic empowerment and links to employment opportunities