

A Qualitative Analysis of Family Support in HIV Care Management for  
Adolescents Living with HIV in Cape Town, South Africa

by

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Thesis submitted in partial fulfillment of  
the requirements for the degree of  
Master of Science in the Duke Global Health Institute  
in the Graduate School of Duke University

2021

ABSTRACT

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## Abstract

Background: South African adolescents living with HIV (ALWH) experience elevated risk for poor HIV-related outcomes due to challenges associated with HIV disease management. While previous research suggests that social support may mitigate poor HIV-related outcomes, we know little about the specific types of family social support that help ALWH achieve better health outcomes or how this support might be better facilitated. This study aimed to address this gap by characterizing the types of social support provided by family members to assist ALWH in their HIV care management.

Methods: We conducted fifty-nine in-depth, semi-structured interviews with ALWH (n=20), their caregivers (n=19), and community stakeholders (n=20) in Cape Town, South Africa. Using deductive and then inductive thematic methods, we triangulated data from these three groups in NVivo to qualitatively analyze family social support.

Results: We identified four types of family social support: instrumental support, appraisal support, emotional support, and informational support. Families provided crucial instrumental support through treatment reminders and attending clinic appointments with ALWH. Families also acted as strong sources of appraisal support to help ALWH reflect upon the importance of medication adherence by promoting future orientation and HIV normalization. Similarly, families facilitated adherence through emotional support, such as motivating ALWH and demonstrating interest in their health. Lastly, families offered informational assistance to educate adolescents about managing HIV treatment challenges, such as side effects.

Conclusion: In characterizing family social support, our findings highlight sources of struggle and possible solutions to the challenges that ALWH face in their HIV care. Our results suggest that ALWH and providers rely heavily on families to distribute these four types of support in HIV care, emphasizing the importance of exploring how to better facilitate and replicate this support. Understanding these types of social support is a crucial step to identifying potential gaps in care and possible intervention strategies. As such, future research should inquire about the efficacy of incorporating these types of social support into interventions to assist ALWH in their HIV care management.

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## Acknowledgements

First and foremost, I would like to thank and dedicate this work to the adolescents and families who participated in this study. I feel honored to have learned from your personal experiences, your struggles, and your triumphs. You have granted me a truly unique perspective that has only strengthened my future commitment to global health work in alleviating health disparities. I hope that this work contributes meaningfully to better the understanding of family social support and assists in developing future interventions to improve outcomes for adolescents living with HIV.

This work would not have been possible without the help and support of my mentor, Dr. Tiarney Ritchwood, and the other members of her research team who collected the data responsible for this study. I would like to thank Dr. Ritchwood for her incredible support throughout every step of this research process. Your passion and devotion to reducing health disparities are inspiring, and I feel incredibly privileged to have had the opportunity to collaborate with you in your work.

Lastly, I would like to thank my family for their unending support throughout my graduate program. The instrumental support, appraisal support, emotional support, and informational support that you have provided me helped make this work possible, and your support continues to fuel my desire to find innovative ways to support the health of all individuals in our global community.

# 1. Introduction

South Africa has the greatest number of adolescents living with HIV (ALWH) in the world, with an estimated 360,000 adolescents between the ages of 10 and 19 living with the virus (UNAIDS, 2020). In 2019, South Africa alone accounted for more than 20% of all ALWH globally, with a disproportionate number of infections among females (UNICEF, 2020). Compared to older and younger age groups, ALWH typically exhibit poorer HIV care management, namely lower levels of adherence to their medications and inconsistent clinical engagement, also called retention in care (UNICEF, 2016, 2018). Poor HIV care management can directly impair long-term viral suppression and increase the risk that ALWH further spread the virus (Nachega et al., 2009; UNAIDS, 2019; UNICEF, 2020). Additionally, adolescents with high viral loads are at increased risk for severe morbidity and mortality because of symptoms like immune suppression, susceptibility to opportunistic infections, and problems with physical functioning (Adejumo et al., 2015; Gill et al., 2002). With these challenges in mind, the United Nations Children's Fund (UNICEF) notes that prioritizing treatment for this age group is vital to prevent new HIV infections and improve the health of adolescents currently living with HIV (UNICEF, 2020). Given the disproportionate burden of HIV on adolescents in South Africa, ALWH in this country require unique types of support to address their current needs and challenges with successful HIV care management.

One possible approach to help facilitate adolescents' HIV care management in South Africa is strengthening family support in HIV care. In addition to providing general child care and support, South African families are involved in HIV care for ALWH in several ways, including providing treatment reminders and offering emotional

support to help adolescents cope with their diagnosis (Petersen et al., 2010). Systematic reviews and other qualitative studies of adolescent engagement in HIV care across sub-Saharan Africa have found that families of ALWH are reported critical to maintaining successful retention in care and encouraging medication adherence, while a lack of family support is linked to poor progression in HIV care (Li et al., 2010; Petersen et al., 2010; S. Williams et al., 2017). Even though families are acknowledged as important to adolescent outcomes, there have been few evidence-based interventions to facilitate family support for ALWH in South Africa (Bhana et al., 2014; Kuo et al., 2016; MacPherson et al., 2015). One possible reason for this lack of research is that family support in HIV care is not well characterized for this population. To respond to this gap in the existing literature, our study aimed to better characterize the social support family members provide ALWH in their HIV care management with hopes of informing future evidence-based interventions.

To understand the context of family support for ALWH, it is first necessary to discuss the literature on challenges faced by this population in their treatment management (see Section 1.1). Additionally, it is important to understand the current state of research on social support for adolescents living with HIV (see Section 1.2). Given the current state of research, Section 1.3 will outline the aims of this thesis project and potential contributions to the current body of work on family support for ALWH.

## 1.1 The State of Adolescent HIV Care and Treatment

The World Health Organization (WHO) notes that knowing one's HIV status from a confirmed diagnostic test is vital to accessing prevention and treatment services like antiretroviral therapy (ART), which is recommended for all PLWH (CDC, 2019a;

WHO, 2020). Adherence to these ART regimens helps to reduce one's viral load until one is considered virally suppressed and resultingly noninfectious (WHO, 2020).

Retention in care, defined as sustained, regular, and scheduled HIV care and ART adherence, is paramount to maintaining viral suppression and reducing morbidity and mortality (CDC, 2019b). As a way to measure global progress on these indicators, the Joint United Nations Programme on HIV and AIDS (UNAIDS) developed the 90-90-90 targets in 2014 to eliminate HIV/AIDS as a major public health concern by 2030 (UNAIDS, 2014). These goals refer to ensuring that 90% of people living with HIV know their status, 90% of people living with diagnosed HIV are on ARTs, and 90% of people living with diagnosed HIV are virally suppressed (UNAIDS, 2014).

Adolescents in sub-Saharan Africa are substantially behind younger and older age groups in achieving the 90-90-90 targets (Adejumo et al., 2015; Mukonda et al., 2020; UNAIDS, 2016; van Wyk et al., 2020; Wong et al., 2017; Zanoni et al., 2016). Global HIV-related mortality increased for adolescents from 2000 to 2013, while mortality for younger and older age groups declined during this time, suggesting poorer adolescent retention and adherence (UNAIDS, 2015). Although UNAIDS does not report statistics on the 90-90-90 targets for adolescents aged 10-19 in South Africa, it estimates that 63% of children under 15 initiated and were on treatment in South Africa in 2019 (UNAIDS, 2019). This lack of data on older adolescents is troublesome, given that studies suggest older adolescents have historically had lower rates of ART initiation and viral suppression (Evans et al., 2013; Maskew et al., 2019; UNAIDS, 2016; Zanoni et al., 2016). Maskew et al. (2019) found that less than 50% of South African adolescents aged 15 to 19 initiated ARTs in a cohort study from 2006 to 2016, while a systematic review

by Zanoni et al (2016) estimated that less than 10% of South African adolescents aged 15-24 were virally suppressed in 2013. Those that have initiated ART may have more improved outcomes, with one South African study finding that of 1,059 adolescents aged 10-19 years old who initiated ART in government clinics, 83.5% reported full clinic attendance in the past year, 63.6% reported full ART adherence in the past week, and 32.5% had an undetectable viral load in 2015 (L. Cluver et al., 2018). These numbers are still well below the 90-90-90 targets set forth by UNAIDS, indicating that treatment retention and adherence remain major challenges for adolescents and young PLWH.

The current literature attributes these challenges with treatment retention and adherence in care to a variety of factors associated with the HIV care experience for ALWH. Qualitative studies in Cape Town and KwaZulu-Natal, South Africa identified negative clinic factors like visit frequency, wait times, discrimination and stigma, and scheduling as barriers to remaining in care (Ritchwood, Ba, et al., 2020; Zanoni et al., 2019). A retrospective cohort analysis of ALWH in South Africa found that clinics with services tailored towards adolescent-specific needs, like flexible clinic opening times and peer support groups, had higher rates of retention and viral suppression than pediatric clinics (Zanoni et al., 2017). Likewise, systematic reviews report common challenges with treatment adherence for ALWH, including managing side effects, treatment fatigue, stigma, lack of knowledge about treatment, and forgetfulness (Claborn et al., 2015; Hudelson & Cluver, 2015). Exposure to stigma and discrimination from teachers, students, family members, friends, and even HIV care providers can further contribute to nonadherence because of the psychological toll it takes on ALWHs (Adejumo et al., 2015; Armstrong-Mensah et al., 2019; Nyogea et al., 2015; Pantelic et al., 2017; S.

Williams et al., 2017). On the other hand, providing education about treatment and HIV/AIDS has been shown to facilitate adolescent adherence, since adolescents may have limited knowledge about HIV preventative measures (Hudelson & Cluver, 2015; Mesic et al., 2019; UNAIDS, 2019). Unlike older PLWH, ALWH grapple with these challenges while also navigating pivotal developmental stages, both physically and psychologically (Christie & Viner, 2005). As such, ALWH may have greater difficulty maintaining adherence and emotional well-being due to their stage in development; yet, some contexts do not adequately incorporate adolescent development into HIV disclosure and education (Britto et al., 2016; Christie & Viner, 2005).

These challenges that ALWH experience in managing HIV have been noted to differ by sociodemographic factors, like gender, age, and mode of transmission, as well as psychosocial factors like self-efficacy and mental health diagnosis (UNICEF, 2016; P. L. Williams et al., 2006). It is known that females are disproportionately burdened by HIV in South Africa, having an increased likelihood to contract the virus than males, as well as worse retention in care and greater likelihood to miss clinic appointments than males (Mesic et al., 2019; UNAIDS, 2019; van Wyk et al., 2020; P. L. Williams et al., 2006). Even though adolescents are known to experience unique risks, there have even been differences reported between older and younger adolescents, with one study finding that older ALWH ages 15-19 were susceptible to worse retention in care than ALWH younger than 15 (van Wyk et al., 2020). The mode of transmission, either behaviorally or perinatally acquiring HIV, also presents unique challenges to each group in sub-Saharan Africa specifically (Sherr et al., 2018). A South African study conducted by Sherr et al. (2018) provided evidence of improved adherence, higher retention, and better treatment

by providers for ALWH with perinatally acquired HIV, compared to those with behaviorally acquired HIV, who had higher rates of depression, anxiety, and stigma. With these challenges and disparities in mind, studies have strived to find ways to reduce the burden of these barriers and facilitate adherence, one of the most prominent being social support (Murphy et al., 2004).

## 1.2 Social Support

Social support is an important positive and protective factor in HIV care engagement and treatment adherence for PLWH, especially ALWH (Abramowitz et al., 2009; Ashton et al., 2005; Kelly et al., 2014; Kunutsor et al., 2011). Although ALWH may receive social support from multiple sources, like community health workers, friends, and religious groups, family social support is particularly relevant for ALWH because of close family proximity and increased likelihood of family members knowing their status (Denison et al., 2015). However, social support has been defined using different definitions, with some studies using pre-established quantitative scales and others using various theoretical frameworks (Casale et al., 2019; Coursaris & Liu, 2009; Cummings et al., 2014; Iwelunmor et al., 2006; Mo & Coulson, 2008). Consequently, it is important to consider how some of these definitions and frameworks are used to encapsulate social support (Section 1.2.1) before exploring the specific functions and potential benefits of family-provided social support for ALWH (Section 1.2.2).

### 1.2.1 Types of Social Support

Social support has been described using different theoretical models and constructs, with definitions varying by study area and authors. One review of the social support literature yielded 30 definitions of social support, each using a combination of



different components like temporality, intentionality, satisfaction, and the type of service or support being provided (P. Williams et al., 2004). Despite these inconsistencies, one commonly-used framework for partitioning types of support can be found in a conceptual analysis of social support by Langford et al. (1997) that divides social support into four main categories: 1) Instrumental support, 2) Emotional support, 3) Appraisal support, and 4) Informational support. The authors conclude that instrumental support takes the form of tangible goods and services and concrete assistance. Communication that conveys empathy, caring, love, and perception of support is termed emotional support. Appraisal support is defined as communicating thoughts, ideas, or concerns to promote reflection and self-evaluation. Lastly, informational support is defined as the provision of information that one can use to solve problems.

These categories have been utilized and interpreted differently by HIV researchers, with some adding new classifications, like network support, or alternative phrasings, such as esteem support instead of appraisal support (Coursaris & Liu, 2009; Cutrona & Suhr, 2016; Denison et al., 2015; Iwelunmor et al., 2006). However, despite varying interpretations, these classifications for social support nonetheless provide a useful lens for identifying the types of social support that enable ALWH to engage in HIV care. Perhaps to circumvent different subcategories of support, some studies have instead chosen to study social support in a more holistic perspective. As an example, satisfaction with social support has been another measure used to quantify the benefits of social support (Abramowitz et al., 2009; Ashton et al., 2005). Two studies found that greater satisfaction with social support was associated with decreased negative outcomes like poor adherence and depression, implicating support satisfaction as an important

indicator of social support. To arrive at this conclusion, Abramowitz et al. (2009) assessed satisfaction separately for family and friends using a Likert scale, finding satisfaction with family support as a strong predictor of overall social support measured using a validated Social Support Survey.

### 1.2.2 Family Support

Despite these varying definitions of social support, most evidence points to the conclusion that the provision of social support by family members is associated with or linked to improved outcomes for PLWH, especially ALWH (Bhana et al., 2020; Casale et al., 2015; Cavazos-Rehg et al., 2020; Damulira et al., 2019; Graves et al., 2018; Holtzman et al., 2015; Petersen et al., 2010; S. Williams et al., 2017). For example, a South African study found that strong caregiver support was associated with improved behavioral, emotional, and prosocial outcomes among ALWH (Casale et al., 2015). Some studies have even suggested that family support may be more effective than other sources of support for ALWH, with a Ugandan study finding social support to be associated with improved adherence only when it was provided by family members, as opposed to teachers, classmates, and friends (Damulira et al., 2019; Denison et al., 2015). The current literature further indicates a lack of family support is detrimental to HIV care management for ALWH (MacCarthy et al., 2018; S. Williams et al., 2017). These findings suggest that, beyond being beneficial, family support might be essential for treatment adherence and other positive outcomes.

Better understanding these unique functions of family social support for ALWH in their HIV care management has important implications for informing future interventions. Resultingly, researchers in sub-Saharan Africa have sought to characterize

family support to inform future interventions. Ashaba et al. (2019) concluded that the most important types of family support are emotional support that provides hope and acceptance and instrumental support related to medication adherence, according to focus groups with Ugandan ALWH. A study in Zambia reported similar findings, suggesting that more meaningful support can come from families of ALWH because oftentimes HIV is only managed within the home (Denison et al., 2015). Other studies have identified instrumental support, like monetary assistance and medication reminders, and appraisal support, such as promoting goal-orientation and acceptance, as factors that improve resilience and adherence among PLWH and ALWH (Cummings et al., 2014; Mburu et al., 2014; Petersen et al., 2010; Woollett et al., 2016).

Despite being characterized in other contexts in sub-Saharan Africa, family support in HIV care is not well described in townships within South Africa (Bhana et al., 2020). Quantitative studies in South Africa provide evidence for the benefits of general family social support without indicating the specific aspects of support that are beneficial or lacking (Casale et al., 2015; Ncama et al., 2008). Similarly, previous family-based interventions for ALWH in South Africa have used strategies like increasing caregiver-child communication and improving family cohesion to improve health outcomes, rather than targeting specific facets of family support (Bhana et al., 2014; van Rooyen et al., 2016). The lacking characterization of family support in Cape Town, South Africa, presents a gap in knowledge for designing evidence-based, family-centered interventions targeted at improving social support for ALWH. Given the suggestive benefit of family support for ALWH, researchers should respond to this gap to better understand how family involvement in HIV care management can be facilitated (Bekker et al., 2015;

Bhana et al., 2020; Holtzman et al., 2015; MacCarthy et al., 2018; MacPherson et al., 2015). This study was conducted to respond to the lack of research characterizing family support in adolescent HIV care in South Africa with hopes of informing future social support interventions, as outlined below in the study aims.

### 1.3 Aim

Identify and characterize the role of family social support in adolescent HIV care management.

Because adolescents often live with and are still dependent on family members, there are unique circumstances that may influence treatment management for ALWH specifically, as opposed to their adult counterparts. Providers, as well as ALWH, often rely on family members to provide support to ensure that HIV is successfully managed and treated. However, there is a lack of literature describing family social support in the context of adolescent HIV care. To address this dearth of evidence, this study characterized the types of support families provide adolescents in HIV care. Characterizing how family systems support adolescent HIV care management can provide insight about current care challenges, as well as identify possible solutions for overcoming barriers to successful adherence and retention in care.

## 2. Methods

### 2.1 Study Setting

Data collection for this study occurred in Cape Town municipality within Western Cape, South Africa (see Figure 1). Cape Town is the second-largest city in South Africa, with a population of about 4.2 million people in 2016 (*Cape Town, South Africa Population*, n.d.).



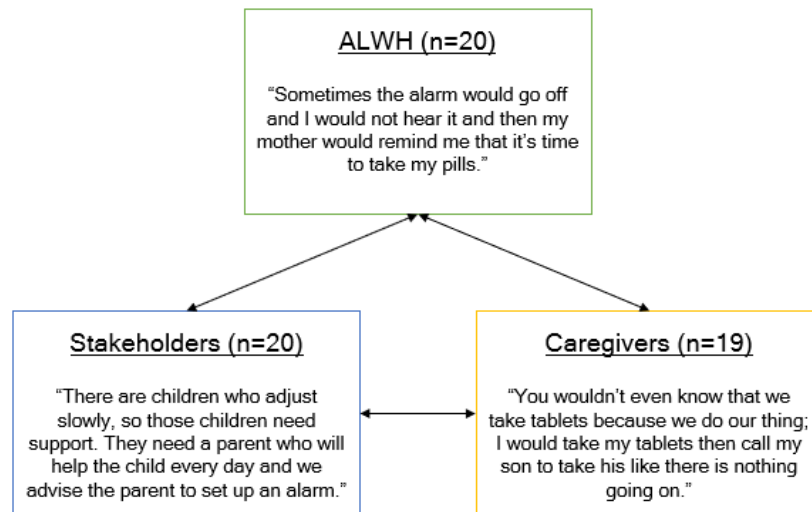
**Figure 1:** Cape Town, South Africa (*Google Maps*, 2021)

According to the 2011 census, 42.4% of individuals identified as mixed race, 38.6% as Black African, and 15.7% as white (Department of Statistics South Africa, n.d.). Cape Town has a youth unemployment rate of 31.9% and a general unemployment rate of 23.9%, with an average household size of 3.3 individuals (Department of Statistics South Africa, n.d.). Forty-seven percent of households reported an annual income of less than R38,200 or 5,295 USD, according to 2011 exchange rates (Department of Statistics South Africa, n.d.). In 2012, the “South African National HIV Prevalence, Incidence and Behaviour Survey, 2012” reported an HIV prevalence of 5.2% in metropolitan Cape

Town and 5.0% in Western Cape province, with an estimated 4.4% prevalence among youth ages 15-24 in Western Cape (Shisana et al., 2014).

## 2.2 Study Design

This analysis utilized data from a study conducted between May and September 2016 in Cape Town, South Africa. Fifty-nine semi-structured, in-depth interviews were conducted in-person with ALWH, their caregivers, and community stakeholders. Data from all 59 interviews are included in this analysis to allow for data triangulation (see Figure 2). The study recruited participants from local HIV clinics serving townships and informal settlements and a variety of local organizations that interact with ALWH in townships within Cape Town, South Africa.



**Figure 2:** Visual Example of Data Triangulation during Thematic Analysis

## 2.3 Participants

Study participants were recruited from three main populations: ALWH (n=20), their caregivers (n=19), and community stakeholders (n=20). The study's principal investigator decided a priori to conduct a total of 60 interviews split evenly among

populations of ALWH, their caregivers, and stakeholders to aim at achieving thematic saturation within and across each group, based on peer-reviewed recommendations on qualitative methods (Guest et al., 2016). ALWH were eligible to participate if they were between the ages of 13 and 19 years old and identified an eligible caregiver to also participate in an in-depth interview. Caregivers were eligible to participate if they were at least 21 years old and a primary caregiver to an ALWH enrolled in the study. Both parties provided either assent or consent before study participation (see Section 2.3). As such, there were 20 corresponding dyads enrolled, each consisting of an ALWH and their primary caregiver. Community stakeholders were defined as individuals working for local organizations, such as faith-based groups, clinics, and social service organizations, that provide services for ALWH. Stakeholders were deemed eligible to participate if they met this criterion, were at least 21 years old, and possessed knowledge of or involvement with ALWH. All participants were required to demonstrate an understanding of study procedures and be willing to be audio-recorded during an in-depth interview of no more than 2 hours.

#### 2.4 Data Collection Procedures

Adolescents and their primary caregivers were recruited from an HIV clinic in Cape Town, South Africa. Stakeholders were identified and recruited from local organizations that provide services for ALWH, including HIV clinics and churches. All participants were recruited using convenience sampling methods by research assistants in person and over the phone. Upon expressing interest and agreeing to participate, participants were enrolled in the study, and interviews were scheduled. Interviews were conducted in either isiXhosa or English by bilingual research assistants. Interviews with

ALWH and their caregivers took place in a private office adjacent to the HIV clinic, while interviews with stakeholders occurred in a private office at their place of work. As an ethical consideration, the research assistants who conducted interviews, although part of the broader Cape Town community, were specifically chosen from communities different than the target population to prevent unintentional disclosure.

Participants were consented or assented before starting the interview. Participants over the age of 18 provided written informed consent, while participants under the age of 18 provided written informed assent. Parental consent was also obtained on behalf of ALWH who were under the age of 18. The consent and assent processes were conducted in either English or isiXhosa based on each participant's preference. Caregivers and ALWH were informed their answers would be confidential and neither caregiver nor ALWH would know the other's responses to protect the wellbeing of participants and encourage accurate testimonies. Interviews were audio-recorded and typically lasted between 45 minutes and 1.5 hours. Upon completion of the interview, participants were compensated with 80 Rand (8 USD). The study's protocol was approved by institutional review boards at the Duke University Health System, the Medical University of South Carolina, the University of Cape Town Ethics Committee, with additional clinic access approval obtained from the Western Cape Provincial Department of Health.

## 2.5 In-Depth Interview Guide

The interview guide was developed using the socio-ecological model as its theoretical framework (Bronfenbrenner, 1977). The guide consisted of questions related to different aspects of each participant's community, HIV care and treatment, family involvement in HIV care, and perceptions of sexual health practices. Because the



interview could be conducted in either English or isiXhosa, the interview guide was translated from English to isiXhosa, back-translated, and edited to ensure that questions held their appropriate meaning in both languages.

The questions most relevant to this analysis pertained to family involvement in HIV care. Modifications were made to ask ALWH and caregivers about their specific experiences, whereas stakeholders were asked to respond generally using the extent of their knowledge and experiences. Each participant was asked a variation of the following three questions:

1. How are families involved in adolescent HIV treatment?
2. How should families be involved in adolescent HIV treatment?
3. How does family involvement impact adolescent engagement in HIV care?

Participants were prompted to explain their responses if they did not respond to the question in detail. Although these questions were the main focus of this analysis, family involvement was also described in other sections of the interview due to the semi-structured nature of some questions. Thus, the entirety of each interview was examined for relevant content.

## 2.6 Data Analysis

Two research assistants translated and transcribed the interviews. A third research assistant performed quality control checks to ensure that the translations and transcriptions were accurate. Data were de-identified for all participants. Interview transcripts were uploaded to Atlas.ti version 7. The team utilized a deductive approach when designing the interview guide and applied this approach to their initial review of the data and structural coding. Afterward, an inductive approach, described in more detail

below, was used to better understand the different types of social support that were elicited from the participant interviews.

At the start of this analysis in April 2020, a concise codebook was created with codes to capture social support, ultimately utilizing four main types of support compiled from literature reviews: 1) instrumental support, 2) emotional support, 3) appraisal support, and 4) informational support (Langford et al., 1997). This codebook was created and refined using a report generated from the initial structural coding conducted in 2016, which contained references to family involvement. Codebook definitions were created and refined for each type of social support, undergoing four initial revisions with the principal investigator of the study. The aforementioned coding report was formatted into a word document and uploaded to QSR International's NVivo version 12 software, along with the latest version of the codebook (see Appendices A and B).

Two members of the research team (VM: primary researcher, LH: research team member) used an inductive approach to classify each mention of family involvement by the corresponding type(s) of social support according to the codebook's criteria. The initial structural coding report was partitioned and coded in thirds by each coder independently. Each coder compared their results after each third of the report to update the codebook. The codebook's definitions were refined twice more, after which each coder recoded the data to ensure reliability with the refined codes. The final inter-coder reliability exceeded 90 percent agreement.

Upon ensuring consistent coding reliability with the updated codebook, the full interview transcripts were uploaded into NVivo version 12 and coded by a single member of the research team (VM). Transcripts were reviewed one at a time and read from start to

finish each time. After reading and coding each interview, memos were written for the specific interview to identify potential emergent themes and quotes that could be used for reference in the analysis. A check-in was performed with the principal investigator after coding about half of the interviews (n=25) with relatively even proportions of ALWH, caregivers, and stakeholders. A subset of coded data from the interviews was examined for agreement as an unofficial way of ensuring that there was still strong inter-coder reliability. Upon confirming this, the remainder of the interviews were coded.

Data were examined for emergent themes using a data reduction matrix from a majority of the interviews. This data reduction matrix enabled the research team to readily identify and organize emergent subthemes within each type of social support. When appropriate, subthemes were further broken down into sub-subthemes (referred to as subthemes as well). Relevant emergent subthemes were identified by analyzing the frequency of emergent themes across all participants and within categories of participants (e.g. stakeholders versus caregivers), as well as through examining themes that appeared or were identified as culturally relevant. These subthemes were then added to the codebook and underwent revisions with the principal investigator. After identifying emergent subthemes and creating corresponding subcodes for each type of social support, all references within each type of social support were recoded using the relevant subcodes. Finally, the emergent subthemes were then compared by their frequency of occurrence and characterized in the participant's category. This method of data triangulation across categories of ALWH, their caregivers, and stakeholders allowed for increased validation of themes (see Figure 2).

### 3. Results

#### 3.1 Demographic Characteristics

**Table 1.** Participant Demographic Characteristics (n=59)

	ALWH n=20	Caregivers n=19	Stakeholders n=20
Gender			
Female	14	19	11
Male	6	-	9
HIV Transmission Route			
Perinatally acquired	20	-	-
Behaviorally acquired	-	-	-
Ethnicity			
Black African	20	19	19
White	-	-	1
Highest level of education <sup>1,2</sup>			
Primary school	7	2	-
High school	9	17	-
College	1	-	-
University	1	-	-
Age (years)			
Mean (Range)	15.3 (13-18)	41.8 (26-64)	35.4 (23-64)

<sup>1</sup> Stakeholders were not asked their highest level of education  
<sup>2</sup> Two ALWH did not provide their highest level of education

The final study sample consisted of ALWH (n=20), their caregivers (n=19), and community stakeholders (n=20). One caregiver was unable to be contacted after enrollment, but the ALWH was still interviewed (non-response rate of n=1). Most participants were female across ALWH (n=14/20), caregivers (n=19/19), and stakeholders (n=11/20). All ALWH had perinatally acquired HIV. All ALWH and caregivers reported being Black African. Nineteen stakeholders reported being Black African and one stakeholder reported being white. Most ALWH reported receiving some high school education (n=11/18), while the remainder reported primary school as their highest level of education (n=7/20). Most caregivers reported having a high school level of education (n=17/19). The mean age was 15.3 years old for ALWH (median=15), 41.8

years old for caregivers (median=39), and 35.4 years old for stakeholders (median=34).

In order of greatest to lowest frequency, caregivers included biological mothers, adoptive mothers, aunts, older sisters, and grandmothers. In order of greatest to lowest frequency, stakeholder professions included: community facilitators or mobilizers, HIV counselors, youth coordinators, doctors, a social worker, a pastor, and a childcare worker.

### 3.2 Social Support Themes

Aim 1 of this study sought to characterize the types of support provided by the family members of ALWH. Four types of social support emerged from analyses of familial involvement in adolescent HIV care management: appraisal support, emotional support, informational support, and instrumental support, each defined in Table 2.

**Table 2.** Defining Types of Social Support

Appraisal support	Promotion of positive self-evaluating practices
Emotional support	Provision of care, empathy, love, and trust that improve perceived support
Informational support	Provision of information to assist in problem-solving
Instrumental support	Concrete assistance and provision of tangible goods and services
* Definitions were adapted from Langford et al. (1997)	

Table 3 provides the frequency of each type of support across ALWH, caregivers, and stakeholders. As shown in the table, instrumental support was most frequently mentioned by ALWH (n=20/20), caregivers (n=19/19), and stakeholders (n=14/20). This was followed by appraisal support, emotional support, and informational support.

**Table 3.** Frequency table of social support <sup>1</sup>

	ALWH n=20	Caregivers n=19	Stakeholders <sup>2</sup> n=20	Total n=59
Instrumental	20	19	14	53
Appraisal	10	14	10	34
Emotional	7	13	12	32
Informational	2	16	7	25

<sup>1</sup> Frequency values indicate the total number of participants in each category that endorsed a given theme. Participants could endorse more than one type of support or none

<sup>2</sup> One stakeholder did not mention family social support

The four identified types of support were each explored in more detail (see Sections 3.3-3.6) for specific subthemes that characterize how families specifically engage in each type of support. Although the themes are described below in order of frequency, each type of support provided by family members served unique and essential functions for ALWH.

### 3.3 Instrumental Support

Instrumental support refers to the provision of concrete assistance and tangible goods and services (see Table 2). The most frequently mentioned theme, instrumental support was endorsed by over 90% of participants (n=53/58). All adolescents and caregivers mentioned at least one type of instrumental support, while 14/20 stakeholders referred to instrumental support. Two main subthemes emerged for instrumental support, namely treatment-related support (n=39/59) and clinic-related support (n= 37/59). These were broken down into further categories, with frequencies outlined in Table 4 and respective summary descriptions in Appendix B.

**Table 4.** Breakdown of Instrumental Support Frequency (n=59)

	ALWH n=20	Caregivers n=19	Stakeholders n=20	Total n=59
Any Instrumental Support	20	19	14	53
Treatment support	13	17	9	39
Reminders to take pills	13	16	7	36
Physical supervision and monitoring	1	5	3	9
Planning for treatment around others	-	3	-	3
Clinic support	13	14	10	37
Attending clinic appointments	3	7	5	15
Proxy to pick up medication	9	4	2	15
Financial support and transport	3	9	1	13
Appointment logistics and reminders	3	5	3	11

\* Frequency values indicate the total number of participants from each group that endorsed a given theme or subtheme. Subtheme totals (e.g. clinic support) are not expected to add up to each theme's total (e.g. instrumental support) since participants could endorse one or more subthemes or none.

### 3.3.1 Treatment-Related Support

Treatment-related support addressed this challenge through three methods: 1) reminders to take pills, 2) physical supervision and monitoring, and 3) planning for treatment around others. The majority of references to treatment support pertained to some type of reminder or inquiry about treatment (n=36), with caregivers the most vocal group of participants (n=16/19).

#### Reminders to Take Pills:

Participants in all categories were very vocal about treatment support through reminders to take medication throughout the day. This was done in multiple ways – participants described setting up an alarm, using verbal reminders at the time adolescents should take their medication, and inquiring about whether adolescents had taken pills afterward. Stakeholder 1002 signaled the importance of establishing a routine, highlighting that reminders may be far more significant for younger ALWH.

“There are children who adjust slowly, so those children need support. They need a parent who will help the child every day and we advise the parent to set up an alarm and now what I do is to take the phone and set up the alarm whilst the parent is still here [in the office].” Stakeholder 1002

As suggested, some adolescents described setting up an alarm, but some still mentioned not always hearing it or still forgetting, so family members also gave verbal reminders.

“Sometimes the alarm would go off and I would not hear it and then my mother would remind me that it’s time to take my pills.” Youth 2001

Some caregivers even described calling their neighbor or relative at the time for their child to take their treatment if the caregiver was away for some reason. According to participants, these types of verbal reminders establish a routine, with family members

typically reminding the ALWH daily and at the time when they should take their treatment. Caregiver 2001 described this process saying, “You wouldn’t even know that we take tablets because we do our thing; I would take my tablets then call my son to take his like there is nothing going on.” She cited her HIV status as a facilitator of treatment adherence because she reminds her son to take his treatment when she takes hers.

Not all caregivers saw reminders as a necessary part of their role. Some indicated that they needed to remind their child to take treatment at the proper time when they were younger but now their child is self-sufficient. For example, Youth 2005 expressed gratitude for her mother and family reminding her to take her treatment, but her mother (Caregiver 2005) recognized that this was not as necessary anymore when she said the following:

“That child doesn’t need my help because I showed her how to do everything, so even when I’m not there she doesn’t fail when it comes to treatment. I don’t remind her about something when I say, “a certain thing” (treatment) she would say ‘you’re too late I’ve already done it.’” Caregiver 2005

#### Physical Supervision and Monitoring:

According to stakeholders and caregivers alike (n=9), one of the main challenges with only providing a verbal reminder is that sometimes the ALWH will choose not to take the pill. A few caregivers said that they supplement verbal reminders with visual monitoring by watching the child swallow pills before they leave for work or before the child goes to bed. Caregiver 2010 described this physical supervision as a means to make certain that her child is adherent, saying:

“If I’m leaving to look for work, I make sure that I leave after she has taken them as old as she is, I don’t want to trust anyone in the house or another child. I want to make sure that she takes them before the time she usually takes them, with me still there even before she eats, when I’m still there.” Caregiver 2010



Additionally, a few stakeholders were adamant that physical supervision can be necessary even for some of the older adolescents because of a reluctance to take medication (n=3). Two stakeholders who advocated for this sentiment mentioned that many caregivers preemptively give older ALWH too much responsibility to take medication on their own and do not think that physical supervision is necessary since they have been routinely taking medicine for some time. They noted that not physically supervising an ALWH can result in nonadherence and worsening of their health when they have clinic appointments. Stakeholder 1008 advocated for this physical supervision, even for older ALWH, saying the following:

“I mean I think the number one thing would be in – at least in my experience, is adherence, is most teenagers young teenagers up till surprisingly old ages need actual physical supervision and not a reminder and they need someone there to watch them swallow the tablets, and parents think that, you know, just saying, ‘Have you taken your tablets?’ is enough and it's not.” Stakeholder 1008

However, one of the major barriers to physically supervising ALWH take their pills is having work or other obligations. For some, physical supervision by primary caregivers is not feasible, since they must leave for work. Caregiver 2012 pointed out this challenge, explaining that her child ignores morning pills because she is not around to supervise her, saying:

“Since I used to leave for work early in the morning, I used to set the time for her and that. At 7(am) she should take her pills and at 7 in the evening when I have returned she should drink them again. But then I found that she dodges the morning one and drinks the ones for when I am around.” Caregiver 2012

#### Planning for Treatment around Others:

Some caregivers pointed out that ALWH will not always have the option to take their medication in a private location due to social events or traveling. To ensure that they still can take their treatment, these caregivers discussed the importance of planning as a

way to protect their privacy. For example, one caregiver commented that she would pack pills in small containers, while another said that she makes sure her younger sister puts pills in her pocket before people come over the house so she can easily take her treatment. Another caregiver described explaining to her son that he cannot go on trips when he would be unable to hide or discretely take his medication. Thus, all three caregivers developed strategies for handling situations in which the ALWH would be unable to openly take their pills.

### 3.3.2 Clinic-Related Support

All categories of participants recognized the importance of families assisting ALWH with services they receive from HIV clinics. They described this clinic-related support in four main ways: 1) Attending clinic appointments, 2) Acting as a proxy to pick up medications, 3) Financial support and transport, and 4) Clinic logistics and reminders.

#### Attending Clinic Appointments:

Stakeholders suggested that family members accompany ALWH to their appointments when they are younger. For instance, Stakeholder 1002 described how family members are normally asked to accompany the children to the clinic until they reach a certain age, saying the following:

“Yes, families are usually very supportive with the youth to come to clinics. As a result, we usually ask caregivers to teach the children at 12 years to come to the clinic and accompany them repeatedly” Stakeholder 1002

Caregivers of younger ALWH, typically below the age of 16, noted that family members tend to accompany the adolescent to clinic visits, as long as they do not have other obligations. Younger ALWH also mentioned this, with one adolescent saying, “My

mother accompanies me if she has not gone somewhere or someone else accompanies me.” (Youth 2009)

#### Proxy to Pick up Medications:

One of the main challenges mentioned by ALWH was picking up their medication from the clinic on days when they have exams or are in school. Almost half of the caregiver/ALWH dyads (n=9) referenced someone in the family who collects their pills for them. As such, some participants indicated that family members, like their grandmother, sibling, or parent, go to the clinic to retrieve their medication when they are in school.

“Yes, there are [barriers]. When you’re taking exams at school and you won’t have time then I have to send my older brother.” Youth 2015

Another caregiver offered to pick up medications as an incentive to take treatment, telling her granddaughter, “My child, if you can take your treatment, I’m willing to go and fetch them myself as long as you are diligent in taking them and you go on your dates to the doctors.” (Caregiver 2016) This was not an option for all ALWH – some indicated that they always pick up their medication but that they would like for someone else in the family to do so on their behalf so the long clinic waits do not force them to miss classes or exams at school (n=2). For example, one youth said the following:

“I would like them to help me when I am writing. That there’s someone who volunteers that ‘I will go to the clinic for you to take the pills, you go to school.’” Youth 2012

#### Financial Support and Transport:

Some caregivers provide ALWH with means of transport to clinic appointments by either dropping them off at the clinic or giving them money to take a taxi by

themselves. Caregiver 2001C also described providing money for food when her son is at the clinic because sometimes the long wait results in him spending most of the day at the clinic. A common theme across caregivers who described providing transport money was that there was not always money available (n=4/9). Caregiver 2013 described how she relies on her sister to either pay for the adolescent's transport or drive her herself when she does not have transport money:

“Sometimes if I don't have money for her to go to the doctor, my sister takes out the money to go to the doctor...and sometimes if there is no money, maybe I don't have a chance to bring her here, she (sister) brings her” Caregiver 2013

#### Clinic Logistics and Reminders:

Caregivers and ALWH both described the importance of knowing the appropriate clinic dates, so they do not miss their appointments due to the difficulty in rescheduling (n=11). Caregivers accomplished this by checking the adolescent's clinic card, asking them when their next clinic appointment is, or reminding them of an upcoming appointment.

“What helps him is me, because when we come back from the clinic I always check when we will go back and then I look at his card. So we both remind each other. So he also says, ‘Aunty, my date is on a certain day.’” Caregiver 2004

Two caregivers mentioned that they follow up with their child if they miss an appointment to inquire why they did not go and re-emphasize the importance of not missing their clinic dates. One caregiver explained reaching out to the clinic to help reschedule missed appointments, while another described contacting the clinic to change the adolescent's doctor because he was not receiving appropriate attention from the doctor. They also advocated on behalf of the ALWH to inform teachers of the ALWH's status and their clinic appointments.

“At school, we also told her teacher... now, when she comes to the clinic, she comes. If she doesn’t want to send the letter she doesn’t. She just tells her that ‘I was at the clinic teacher.’”  
 Caregiver 2015

### 3.4 Appraisal Support

Appraisal support describes the promotion of positive self-evaluating practices (see Table 2). A total of 34/59 (57.6%) participants emphasized the importance of appraisal support at least once, with caregivers mentioning it the most (n=14) followed by ALWH (n=10) and stakeholders (n=10). Two subthemes emerged from participant interviews that further describe how family members provide ALWH with appraisal support: 1) HIV normalization and 2) promoting future-orientation. Table 5 provides a breakdown of appraisal support by frequency (see Appendix B for descriptions).

**Table 5.** Breakdown of Appraisal Support Frequency (n=59)

	ALWH n=20	Caregivers n=19	Stakeholders n=20	Total n=59
Any Appraisal Support	10	14	10	34
Promoting future-orientation	8	9	4	21
Linking adherence to future success	6	4	3	13
Life and death	3	7	-	10
HIV normalization	2	9	3	14

\* Frequency values indicate the total number of participants from each group that endorsed a given theme or subtheme. Subtheme totals (e.g. HIV normalization) are not expected to add up to each theme’s total (e.g. appraisal support) since participants could endorse one or more subthemes or none.

#### 3.4.1 Promoting Future-Orientation

One subtheme that emerged often among participants of all categories is promoting future orientation to encourage ALWH that they can both manage HIV and live a successful life. However, participants varied in how they described promoting future orientation. Some described successful treatment management as critical to future success (n=13), whereas other participants referenced future-orientation by connecting successful treatment to life and failed treatment to death (n=10).

### Linking Treatment Adherence to Future Success:

One strategy that emerged to promote future orientation is positively framing HIV treatment adherence by linking adherence to achievement of future aspirations and goals. Many individuals used the exact phrase “It is not the end of the world” to explain how even though HIV is portrayed as a lethal and stigmatized disease, it can be successfully managed with treatment without impeding future success. One caregiver used her child’s aspiration of being a social worker to motivate her to think about the benefits of taking her medication. One ALWH similarly mentioned how his family made him realize, “if I take my pills all my things will go well” when talking about his education (Youth 2001). Another related sentiment discussed by some participants was a responsibility to one’s family to adhere to treatment and prove it is possible to live a successful life with HIV. One youth explains that her sister’s expectations of her allow her to make this positive connection between taking pills and future success, saying:

“And then I think that if... like my sister is still expecting something big from me, that I should do for her so now I must take the pills so that I can live and study and be what I want to be.” Youth 2012

### Life and Death:

Other participants described a more negative framing approach used to accomplish the same goal by connecting unsuccessful treatment to death. These participants spoke of a dependency on pills that was often accompanied by rhetorical questioning about whether ALWH want to live, as Youth 2012 describes below. She quoted her aunt who inquired whether she wants to follow the same life trajectory of her mother who died from HIV, saying:

“I didn’t drink the pills and I said, ‘I won’t take pills when I don’t know what they are for’ and then I saw that I was getting sick when I didn’t drink the pills. And then my aunty was saying things like ‘your mother died what do you want to do? Do you want to follow her?’” Youth 2012

Other participants connected HIV medication adherence to the ALWH’s will to live, with one caregiver saying, “If you want to live, you must take your treatment. But, if you don’t want to live, you will stop the treatment” (Caregiver 2002). This explanation frames adherence as a personal choice to live, rather than the previous subtheme which connects adherence to success.

### 3.4.2 HIV Normalization

One theme that emerged in connection to appraisal support was HIV normalization, in which participants described creating a sense of normalcy about living with HIV and taking HIV treatment. A few caregivers emphasized that many individuals without HIV also need to take pills daily for other diseases. For example, one caregiver shares with her granddaughter that her HIV treatment is comparable to the treatment she must take for ulcers.

“I said, ‘I have ulcers... I used to go to [clinic 1] but I was sent to [clinic 2],’ I said, “This is your clinic and I go to [clinic 2]. If I also don’t use my medication properly, I am also going to die so you too just have to eat your treatment and eat healthy just like me.” Caregiver 2003

The caregiver compared her clinical experiences with her granddaughters, drawing similarities between the steps each of them must take to remain healthy. She described that this results in her granddaughter normalizing and redefining her HIV treatment as just normal medication. This quote touches on another similar idea that at least one participant from each group of ALWH, caregivers, and stakeholders referred to in normalizing treatment – normalizing discussions about the treatment routine itself. One stakeholder praised the value in making these discussions “a normal part of the family”

(Stakeholder 1013), a sentiment which is echoed by Caregiver 2003 above in how she compares the logistical aspects of both her and her granddaughter seeking services from clinics.

Additionally, several caregivers mentioned teaching ALWH that they are “like other people” (Caregiver 2002) and “the same as other kids” (Caregiver 2001) to avert internalized stigma and prevent treatment disruptions. Caregiver 2002 stressed that ALWH must be provoked to think about their lives with this attitude of equal potential, saying:

“They need to know that they’re the same as other kids and they need to be strong. They need to know that they can learn like any other kids, they can do anything like other children so that it stays in their minds that they can do anything, you understand?” Caregiver 2002

A few adolescent participants expressed appreciation for this type of support from their families, with one ALWH saying, “Yes, so from that day on when she told me those words, I just kept it to myself... That I’m also just like the rest of the people, I have a bright future and I have a life to live.” (Youth 2006) By normalizing HIV, this ALWH was able to re-appraise the significance of adhering to medication.

### 3.5 Emotional Support

Emotional support is the provision of care, empathy, love, and trust by family members that influences one’s perception of support (see Table 2). Across participants, emotional support was referenced most frequently by caregivers (n=13) and stakeholders (n=12). Emotional support emerged in two overarching subthemes: 1) compassion and affection and 2) encouragement (see Table 6 for frequencies and Appendix B for further descriptions).



**Table 6.** Breakdown of Emotional Support Frequency (n=59)

	ALWH n=20	Caregivers n=19	Stakeholders n=20	Total n=59
Any Emotional Support	7	13	12	32
Compassion and affection	4	10	8	22
Acceptance	1	5	3	9
Expressing interest in well-being	1	4	4	9
Motivation from encouragement	2	4	6	12

\* Frequency values indicate the total number of participants from each group that endorsed a given theme or subtheme. Subtheme totals (e.g. compassion and affection) are not expected to add up to each theme's total (e.g. emotional support) since participants could endorse one or more subthemes or none.

### 3.5.1 Compassion and Affection

One way in which participants characterized emotional support was through providing compassion and affection for ALWH. Often, caregivers (n=10) and stakeholders (n=8) who elicited this theme expressed the desire to influence the ALWH's perception of support so that they felt accepted and loved by other family members after HIV disclosure. This perception of support was described as an essential component of the treatment process for ALWH by making it easier to engage in care. Stakeholder 1004 summarized this sentiment, saying:

“It makes it easier because you know that there is someone, everyone who loves [you]... So once I'm in a house where everyone loves and supports me, it's easy to go to a clinic, to go take treatment...” Stakeholder 1004

With this goal in mind, there were a few different ways in which participants described providing a loving and supportive environment. Many participants simply mentioned providing love and affection. Some specifically emphasized having a family that was accepting, non-discriminatory, non-judgmental, and forgiving (n=9), while others described actively displaying an interest in the adolescent's HIV care (n=9).

## Acceptance

A few words and ideas that participants elicited were non-judgmental, non-discriminatory, accepting, and forgiving. Numerous caregivers and stakeholders explained the significance of families having these characteristics as a prerequisite to providing support to ALWH. One stakeholder did so, saying, “Before they (family) get involved you have to tell them that you have tested for HIV positive. They must not be judgmental, and they must support you from the start until the end.” (Stakeholder 1017) One adolescent explained that this acceptance allows her to talk to her family about taking treatment and ask for help when she needs it, saying:

“It makes me feel, okay. It makes me happy when maybe we buy pills or they talk about other pills... yho...Oh...Okay... It makes me feel happy when they talk about pills because they know I take pills and then they make me think that I shouldn't be disgusted with myself as a person when I am taking the pills and need help.” Youth 2005

Caregivers further specified accepting and forgiving ALWH with behaviorally acquired HIV, with Caregiver 2015 noting, “It makes [staying in care] easy by not bringing back the past like ‘what happened, for you to get it.’” Thus, participants highlighted acceptance as a pre-requisite for comfort and other support.

## Expressing Interest in Well-being

Participants described the necessity of expressing interest in well-being by providing love through active care, involvement, and responsibility in a way that influences one's perception of interest. One of the main methods utilized by caregivers to demonstrate interest is actively questioning adolescents about their experiences with HIV care and check-ins on how they are coping with their HIV management. Some caregivers outlined other strategies they use to console their children when they are feeling fatigued from treatment or alienated by it. A couple of ALWH and caregivers explained how

having a family member show interest in one's care facilitates treatment adherence.

Similarly, caregivers described affirming their care and willingness to be involved in care, seen by Caregiver 2018 saying:

“[I said,] ‘I am your mother and I am everything to you. So, I want you, even when you have a problem, to be able to talk to me and not be afraid... So, you can talk and chat with me.’”

Caregiver 2018

### 3.5.2 Motivation from Encouragement

Participants drew attention to the importance of encouraging ALWH throughout their HIV care management. This ranged from encouraging treatment adherence to encouraging that one remains confident and hopeful. One caregiver emphasized the importance of constant encouragement, saying: “I die today and they (family) don't know that my son is HIV positive, he is going to stop the medication because no one will be there to push him and he is going to keep quiet, you understand?” (Caregiver 2001)

### 3.6 Informational Support

Informational support is the provision of information to assist in problem-solving (see Table 2). Although not cited as frequently, informational support was described consistently by caregivers (n=16) and stakeholders (n=7). It was primarily provided through HIV education, specifically strategies for HIV management. Most stakeholders that described informational support primarily did so through the provision of informational support to family members so that these family members could in turn provide better care for ALWH. Meanwhile, most caregivers shared the information that they provide directly to ALWH. Frequencies are provided in Table 7 (see Appendix B for descriptions).

**Table 7.** Breakdown of Informational Support Frequency (n=59)

	ALWH n=20	Caregivers n=19	Stakeholders n=20	Total n=59
Any Informational Support	2	16	7	25
HIV education	2	15	7	24
HIV management	2	12	5	19

\* Frequency values indicate the total number of participants from each group that endorsed a given theme or subtheme. Subtheme totals (e.g. HIV education) are not expected to add up to each theme's total (e.g. informational support) since participants could endorse one or more subthemes or none.

### 3.6.1 HIV Education

About half of all participants described informational support in the form of HIV education. These participants emphasized the importance of family members being knowledgeable about HIV and how to manage HIV so that they in turn can provide appropriate education for ALWH. Although most described providing information about how to manage HIV, a few participants described filling in gaps in general HIV knowledge.

#### HIV Management

Participants credited family members with providing suggestions about lifestyle and treatment management. Adolescents and caregivers described family members teaching ALWH how to take medication and mitigate side effects. Stakeholder 1007 specified that family members should “[understand] how these antiretrovirals work, if there's side effects, so that when one of the family come and you're experiencing side effects, at least, she's aware. She knows what to deal with.” Multiple caregivers explained that when their child is overwhelmed by side effects, they provide suggestions about which foods to eat with the medication and the time of day they should take it. For example, Caregiver 2016 suggested, “Why don't you use juice or milk or yogurt? ... Why don't you take them when you are about to sleep?” to prevent nausea from

interfering with her child's ability to focus at school. Another way in which caregivers informed ALWH about managing HIV is through teaching responsibility as they get older and more independent in their HIV management. One caregiver described educating her adolescent on how to keep better track of her pills when she has social obligations. A few other caregivers taught their adolescents how to have a proper diet and explained the purpose of taking their medication correctly. Caregiver 2002 emphasized these ideas, saying:

“I tell her to make sure that she takes her treatment and not to miss it, no matter what she is doing, but not to take treatment with alcohol, it will not work.” Caregiver 2002

A couple of caregivers explained that they learned these strategies through attending information sessions and classes at the clinic with their children. On the other hand, lack of knowledge about the disease inhibits a family's ability to provide multiple types of social support, as Stakeholders 1006 and 1012 suggested. They explained that, without the proper knowledge, families may not accept one's status and they may lack the knowledge to make suggestions about treatment, side effects, and treatment reminders. Stakeholder 1012 emphasized the importance of learning this information, saying:

“Others do not have the information or do not have the time to get that information. People would say ‘We were expecting it from you because you were doing this and that’ if diagnosed with HIV. They are judgmental, some put you down but the only one that can support you is the one with information and knowledge. And it will take time for the one to inform the rest of the family. You get that our parents are bullied by our sisters so whatever she says goes. In the family, the person with no information will be the one putting down the HIV positive person.” Stakeholder 1012

## 4. Discussion

### 4.1 Study Findings and Implications

This study aimed to characterize how families support ALWH with their HIV care management in South Africa. Our analysis yielded four main types of social support that were adapted from Langford et al. (1997): 1) instrumental support, 2) appraisal support, 3) emotional support, and 4) informational support. Instrumental support was the most frequently identified type of support provided by family members through treatment support and clinic support. Appraisal support and emotional support followed, having roughly the same number of endorsements. With appraisal support, families assisted ALWH in normalizing HIV and promoting future-orientation. Meanwhile, emotional support was utilized to motivate ALWH in their treatment management and provide comfort through acceptance and interest in one's well-being. Lastly, families provided informational support about HIV management to help adolescents navigate potential challenges like side effects.

This study has important implications for the role of social support in improving treatment retention and adherence for ALWH. Numerous quantitative and qualitative studies have already alluded to the protective role of social support in multiple aspects of HIV care for ALWH and older populations of PLWH living in South Africa and other regions of sub-Saharan Africa (Adejumo et al., 2015; Casale et al., 2019; Iwelunmor et al., 2006; Lowenthal et al., 2014; Petersen et al., 2010; S. Williams et al., 2017). This has prompted researchers to suggest that social support and family support be incorporated in future interventions for PLWHs (Kunutsor et al., 2011; Kuo et al., 2016). However, there is currently a lack of literature characterizing how social support is provided and what

types of social support might be most beneficial. Our findings add to the body of literature on social support by characterizing the role of family involvement in HIV care for ALWH through the four categories of social support, each discussed below. These types of family support can provide insight into how future HIV services and interventions can better support ALWH during their formative stage of development.

### Instrumental Support

Instrumental support emerged most frequently among participants, suggesting that families are tasked with providing material and tangible supportive services like consistent treatment reminders, medication monitoring, and attending clinic appointments with ALWH. This coincides with previous findings that ALWH face increased challenges related to clinic logistics and health care services, suggesting that these types of support may be a vital step to improving treatment adherence (Ritchwood, Ba, et al., 2020). Results from our analysis were also consistent with findings in other regions of sub-Saharan Africa and across different age groups. For instance, studies in Zambia, Uganda, and Mozambique all identified the importance of family-provided instrumental support for PLWHs of all ages, with each study identifying varied themes like medication reminders and financial support (Ashaba et al., 2019; Cummings et al., 2014; Denison et al., 2015; Mburu et al., 2014). Specifically, all categories of participants highlighted the benefit and oftentimes the necessity of physical treatment monitoring and reminding ALWH to take their treatment correctly. Given the ascribed benefit of these practices, our results support previous recommendations that clinics and community groups should inform families or treatment supporters of ALWH about how to assist with systematic

monitoring and providing reminders for adolescents (Holtzman et al., 2015; Kunutsor et al., 2011).

As some participants and other studies have alluded to, caregivers face numerous barriers to providing instrumental support like poverty and other work commitments (Petersen et al., 2010). According to participants, it becomes challenging to coordinate logistically if not many family members know of the adolescent's HIV status or are involved in the adolescent's HIV care, which might prevent family members from accompanying adolescents to the clinic, for example. More impoverished families or caregivers of vulnerable populations of ALWH in South Africa might therefore require even greater support than they currently receive to provide instrumental support (or other types of support) expected of them (Lachman et al., 2014). This finding is also consistent with previous research demonstrating that South African ALWH experience increased perceived social support when they identify more "close" family members and friends in their social network (Ncama et al., 2008). As such, it may be crucial to provide greater support to families and social networks of ALWH so that these groups can in turn support ALWH by being more engaged in their HIV care management (Holtzman et al., 2015; Petersen et al., 2010).

#### Appraisal Support

We found future orientation and normalization of HIV to be essential components of a family's appraisal support across all categories of participants. Other South African studies with ALWH and their caregivers have similarly concluded that areas of needed support include future orientation and self-concept issues (Bhana et al., 2014; Petersen et al., 2010). Caregivers and stakeholders described proactive efforts to instill these positive



appraisal behaviors for ALWH in particular because they are at an age when they are coming to terms with their diagnosis. By further normalizing one's HIV status and promoting future-orientation in the context of treatment adherence, participants outlined methods to foster resilience and reorient ALWH during times of struggle. Because participants in this study discussed these positive self-evaluating practices outside the context of emotional challenges, this prompted the emergence of appraisal support as its own prominent theme, contrary to other studies that categorized related subthemes as components of emotional support to assist with coping (Denison et al., 2015; Iwelunmor et al., 2006; Petersen et al., 2010). For example, participants often mentioned promoting future-orientation as a means of reframing HIV's implications and preventing non-adherence, rather than as a way to cope with one's diagnosis.

Other appraisal support mechanisms similar to those identified in this study have been shown to promote resilience in ALWH in ways that can assist in preventing future challenges with treatment fatigue and stigma (Claborn et al., 2015; Kuo et al., 2019; Woollett et al., 2016). A study of ALWH in Johannesburg, South Africa, found that self-acceptance and goal-orientation, analogous to HIV normalization and linking adherence to future success respectively, were contributing factors to resilience (Woollett et al., 2016). Because these appraisal methods have been linked with resilience in South Africa and other contexts, it might be important to provide families with appraisal support strategies during the disclosure process (Britto et al., 2016; L. D. Cluver et al., 2015). Youth who perinatally acquired HIV might gain the most benefit from this type of intervention because they often require repeated, more thorough disclosure throughout rapid stages of physical and psychological development (Christie & Viner, 2005;

Petersen et al., 2010). Our findings suggest some positive appraisal strategies that could be taught to at-risk ALWH by clinic counselors using mHealth platforms or during treatment support groups, for example. Alternatively, mental health interventions for at-risk ALWH in South Africa could be adapted to facilitate and engage family appraisal support since many youths described this as beneficial to their long-term outlook (Bhana et al., 2014).

Providing youths with these re-appraising strategies during adolescence, when youth are just beginning to develop appraisal skills, may help to reduce disengagement from care when ALWH transition from pediatric or adolescent care to adult care settings (Battles & Wiener, 2002; Christie & Viner, 2005; Ritchwood, Malo, et al., 2020).

However, one study of adolescent girls living with HIV in Zambia showed that appraisal strategies were linked to reinforced stigma, emphasizing the importance of understanding which strategies might be most beneficial (Roberts et al., 2021). More research is necessary to identify what appraisal practices are most beneficial for ALWH and how they can be incorporated into future interventions.

### Emotional Support

Emotional support has been widely accepted as an integral component of social support for ALWH because of challenges like lack of disclosure, internalized stigma, and treatment burden (Haberer & Mellins, 2009; Li et al., 2010; Pantelic et al., 2017; Petersen et al., 2010; Sherr et al., 2018). Our results similarly concluded that families are essential for creating accepting environments and influencing adolescents' perceptions of social support through showing compassion and expressing interest in their well-being. Likewise, our study's results concurred with previous studies that describe the role of

familial emotional support in combatting treatment challenges and difficulties with retention in care (Ashaba et al., 2019; Cummings et al., 2014). Specifically, we found that families accomplish this by providing strong encouragement and motivation for treatment adherence.

Families, therefore, are critical to fostering an accepting and supportive environment for ALWH who live with family members. A systematic review of mental health interventions for ALWH in low- and middle-income countries suggests the promising benefit of family-centered approaches, with most family-strengthening interventions resulting in improved behavioral and mental health outcomes (Bhana et al., 2020). Our findings provide evidence of the specific emotional support mechanisms, such as motivation and expressing interest in the ALWH's care, that could be incorporated into these family-strengthening interventions. However, many of the ALWH in this study, similar to other South African studies, reported only being disclosed to family members, with some being disclosed only to certain family members (Madiba & Mokgatle, 2016). ALWH with limited disclosure and smaller social networks tend to receive less emotional support, thus increasing vulnerability to poor adherence (Ncama et al., 2008).

For those without family or with limited familial disclosure, viable alternatives might include peer support groups, which are already described as beneficial by South African ALWH (Aderomilehin et al., 2016; Zanoni et al., 2019). Whereas our findings and other studies suggest that families tend to provide the most significant support in terms of treatment support and acceptance, peers may provide unique types of support and social acceptance that families alone are sometimes unable to offer (Abramowitz et al., 2009; Coursaris & Liu, 2009; Mburu et al., 2014). More research should examine the

feasibility of engaging other social networks to provide emotional support for adolescents with perinatally acquired HIV, given their limited disclosure and heavy reliance on family members.

### Informational Support

Although fewer participants described informational support, those that did explained its necessity for family support to exist, especially stakeholders. In this study specifically, family-provided informational support appeared useful for providing HIV knowledge and treatment management strategies like mitigating side effects and navigating treatment in social situations as ALWH become more independent in their care. These participants explained that once family members become knowledgeable about HIV and how to support someone living with HIV, there will be more accepting environments, greater family involvement, and improved outcomes for ALWH. Previous studies have similarly characterized families' roles in providing informational support to assist with medication adherence and overall health of ALWH and other PLWH (Bhana et al., 2014; Cummings et al., 2014). This education is particularly important for ALWH in South Africa since studies have shown that adolescents who have taken care of individuals living with HIV lack accurate knowledge about HIV care (De Wet et al., 2019). Due to the benefits of having families supplement this knowledge, studies have advocated for coeducating family members and ALWH about HIV care management (Sam-Agudu et al., 2016).

For families to educate ALWH about these topics, they themselves need to be informed about HIV care; however, some caregivers reported lacking this knowledge until they attended classes at the clinic. There additionally were discrepancies in how

much independence caregivers provided ALWH in their care management. These discrepancies and the lack of knowledge about HIV care are concerning since studies like Petersen et al. (2010) have demonstrated that ALWH who lack information about HIV treatment often report experiencing greater challenges with adherence and coping. Resultingly, some interventions have sought to engage families in HIV health education with family-centered care practices, such as “Family Clinic Day” in Uganda, which provided HIV appointments and health education for families of ALWH (Graves et al., 2018). More research should explore the potential efficacy and feasibility of a similar coeducational approach for families of ALWH in South Africa, given that our study’s participants reported similar experiences and benefits of family involvement. Additionally, clinics or other public services should ensure that services are available for both families and adolescents to learn about essential aspects of HIV care management.

#### 4.2 Study Limitations and Strengths

It is important to consider the findings of this study in light of its limitations. To start, the study sample was limited to a relatively confined geographic region in Cape Town, South Africa. As such, the results of this study may not be generalizable to other areas. However, many of the findings from this study were consistent with other contexts in sub-Saharan and Central Africa, as well as on other continents. Another potential limitation was the composition of the study sample. Participants were primarily female, and all ALWH had perinatally acquired HIV. Families of ALWH with behaviorally acquired HIV may not know of the adolescent’s status or be involved in their HIV care, so family support may manifest differently. Although this might limit some of the implications provided by ALWH and their caregivers about social support, both

caregivers and stakeholders discussed challenges faced by behaviorally and perinatally acquired HIV and discussed family support in light of selective family disclosure.

Given the already lacking literature on social support for this population, the lack of an established standard for qualitatively defining social support limited the ability of this study to assess its findings in the context of previous studies. After considering multiple models of social support, this study identified four specific themes of support: instrumental support, appraisal support, emotional support, and informational support. Although our results concur with previous findings on family support for ALWH, there may be other significant sources of social support provided by other individuals. For instance, studies of social support provided to ALWH in online forums have found an abundance of informational support, which was not as frequently mentioned as other types of support by participants in this study (Coursaris & Liu, 2009; Mo & Coulson, 2008). While a different platform for providing support, these studies of online forums indicate that there may be other aspects of support not encapsulated by this study.

One important consideration related to this study's findings on family support is the influence of adolescent development on the themes that emerged during analysis. Our findings might more accurately reflect support in families with ALWH than in families with older PLWH due to unique factors that are associated with adolescent development, like a desire for increased independence (Christie & Viner, 2005). As such, our findings on family support might not be readily transferable to families who have younger or older populations of PLWH. Additionally, the discordance in frequency of some social support themes between groups of ALWH and caregivers might reflect differing priorities between these groups for the desired types of family involvement. Adolescents may

therefore not desire some of the identified types of family support, despite the ascribed benefits described by caregivers and stakeholders.

There were also some limitations regarding the interview process and study analysis. Regarding the interview process, research assistants received extensive training on qualitative methods. However, some of the earlier interviews, as well as specific parts of the interview guide, did not have a lot of in-depth probing. This could have been due to the length of the interview guide and the number of topics it contained. Resultingly, some responses were not very interpretable because of a lack of clarity and probing. Young ALWH especially had short and vague responses, potentially due to their age and the stigma associated with the topics. Contributing to a lack of literal interpretability, some interviews were conducted in isiXhosa and translated to English for analysis, so some quotes were not able to be analyzed literally because of potential mistranslations. To mitigate this misinterpretation and issues with translation, bilingual research assistants from the area who conducted the interviews also translated them. Finally, it is important to acknowledge that I am a white, US-born, male, which could bias my interpretation of the results from a lack of direct personal experience in this context. Recognizing this bias, I worked closely with other study members to learn about cultural differences and receive feedback from individuals more closely connected to the context.

Keeping in mind these limitations and the solutions employed by this study to combat them, there were also some significant strengths of this study and its analyses. First, data were collected from a diverse participant population containing stakeholders, ALWH, and their caregivers to allow for triangulating data from multiple sources. This ensured that multiple perspectives were represented and created a holistic depiction of

social support. The large sample size of 59 participants permitted data saturation and allowed for subthemes to emerge that might have been overlooked in a small sample. Furthermore, research assistants were from nearby communities, which facilitated developing rapport with study participants. Research assistants were also trained by the study investigators before conducting interviews and met frequently during the interview stage to make sure protocols were being correctly followed.

Another strength of this analysis, this study's codebook underwent multiple revisions by multiple reviewers to establish consistency with the interpretation of themes and subthemes. Of importance, there was a high inter-coder agreement between the two coders for the initial coding step. The principal investigator also contributed greatly to the review and revision of this analysis to ensure that data was interpreted properly in the context of the study population and location. Lastly, even though there is no established standard for defining social support, this study's findings were still mostly consistent with previous findings using other models of social support, suggesting adequate validity and reliability of the themes and subthemes in this analysis.

#### 4.3 Conclusion and Future Directions

This study qualitatively analyzed how family members provide social support to ALWH in their HIV care management. We found that, during a time when ALWH might start to gain more responsibility and greater independence in their treatment management, family involvement is still crucial to their retention and adherence. Our findings demonstrate the recognized importance of social support – specifically instrumental support, appraisal support, emotional support, and informational support – by multiple populations involved in the HIV care process, including community stakeholders,



caregivers, and ALWH. Additionally, our results suggest that families are tasked with providing a significant amount and variety of social support to ALWH, perhaps without receiving adequate support or education themselves due to some inconsistencies in expectations. To provide adequate social support, families must understand the types of needed support and how to best offer them. As a result, this study provides evidence in support of increasing not only caregiver participation and inclusion in HIV care for ALWH, but also family participation as a whole.

Considering these implications, further research is necessary to understand what challenges impair family support and how family support can be facilitated. Researchers should investigate the feasibility and efficacy of incorporating social support into interventions for families of ALWH, as well as alternative sources of support like peers, in clinical and community-based settings to ensure that ALWH have adequate support networks to successfully manage their HIV. Additionally, more research is needed to better understand how different types of social support should be prioritized based on developmental and treatment challenges for ALWH. More research is also needed to assess the generalizability and validity of these findings, given the homogenous characteristics of our study population. In conclusion, families provide unique and beneficial types of social support to ALWH, thus presenting a unique opportunity to help ALWH successfully navigate their HIV care management.

## Appendix A: Codebook, Parent Codes and Descriptions

Table 1 provides the descriptions, adapted from Langford et al. (1997), used to code emergent themes of social support, along with an illustrative quote for each theme.

**Table 1.** Parent Code Descriptions for Each Type of Support

Parent Code	Description	Illustrative Quote
Instrumental support	<p>Use this code for family-provided instrumental support, defined as concrete assistance through tangible goods and services, in HIV care.</p> <p>Examples include ALWH receiving finances, transportation, reminders, and assistance picking up medications.</p>	<p>"Most of the teenagers do come by themselves to the clinic as long as the parent gives them money to get a taxi and not meet with gangsters in the streets, give them transport money and make them come."</p>
Emotional support	<p>Use this code for emotional support from family members directly related to HIV treatment. Emotional support will be defined as: "provision of caring, empathy, love, and trust" that influences one's perception of support.</p> <p>Examples might include families acting as a support group and acceptance of one's status.</p>	<p>"It makes it easier because you know that there is someone, everyone who loves [you]... So once I'm in a house where everyone loves and supports me, it's easy to go to a clinic, to go take treatment..."</p>
Appraisal support	<p>Use this code for appraisal support from family members directly related to HIV treatment. Appraisal support is defined as promoting positive self-evaluation to encourage positive assessment of one's situation.</p> <p>Examples include reaffirming ALWH can live a successful life</p>	<p>"For me, the support is them telling me to take my pills and that if I don't take them my education would end up on the road but if I take my pills all my things will go well."</p>
Informational support	<p>Use this code for informational support provided by family members related to HIV or HIV treatment. Informational support is defined as: provision of information to assist in problem-solving related to living with and treating HIV.</p> <p>Examples include knowledge about treatment side effects</p>	<p>"Through being supportive and understanding how these antiretrovirals work, if there's side effects so that when one of the family come and you're experiencing side effect, at least, she's aware. She knows what to deal with. She understands the HIV and the treatment that you are taking."</p>

## Appendix B: Codebook, Subcodes and Descriptions

Tables 1 through 4 in Appendix A provide a breakdown of identified themes and subthemes. Each table represents one theme of social support identified (e.g. Table 1 for Instrumental Support), with each row in the table representing a unique subtheme. A brief description and illustrative quote are provided for each subtheme.

**Table 1.** Breakdown of Instrumental Support Descriptions (n=59)

Subcodes		Description	Illustrative Quotes
Treatment support	Reminders to take pills	Family members remind ALWH to take their pills or inquire if they have taken them	“Sometimes the alarm would go off and I would not hear it and then my mother would remind me that it’s time to take my pills.” Youth 2001
	Physical supervision and monitoring	Family members are physically present when ALWH take their pills	“You’ll see them leave the other children, come into the house, take the tablet, ‘Mama’, [opens her mouth to show that they have swallowed the tablet] and off they go” Caregiver 2003
	Planning for treatment around others	Family members prepare for situations when ALWH cannot discretely take pills	“If we are going out and we are going to come back late everyone takes... I’ve got small plastics sachets which I put the tablets in.” Caregiver 2003
Clinic support	Attending clinic appointments	Family members attend clinic appointments with ALWH	“I make sure that on clinic days he comes to the clinic if I am around, I make sure that I come with him to the clinic.” Caregiver 2017
	Proxy to pick up treatment	Family members pick up medication from the clinic on behalf of the ALWH or ALWH expressed this desire	“When I haven’t gone to the clinic, they, my mother can go, and my sister can go and collect the pills for me.” Youth 2018
	Financial support and transport	Family members provide money and transport when ALWH needs to go to clinic	“I give her money for the taxi.” Caregiver 2012
	Appointment logistics and reminders	Family members remind ALWH about their clinic dates and help with scheduling and coordinating care	“I make sure that the dates are stuck to and I make sure of the child’s [clinic] card, the times for the pills, you see?” Caregiver 2018

**Table 2.** Breakdown of Appraisal Support Descriptions (n=59)

Subcodes		Description	Illustrative Quotes
Promoting future-orientation	Linking treatment adherence to future success	Families frame successful HIV treatment adherence in terms of successful future aspirations	“For me, the support is them telling me to take my pills and that if I don’t take them my education would end up on the road” Youth 2001
	Life and death	Families frame successful HIV treatment adherence in terms of life and death	“When they shout at you, ‘Why aren’t you taking your pills, you know you will die!?’” Youth 2013
HIV Normalization		Adolescent’s HIV care, treatment, and self-concept are normalized by families to reduce stigma	“It’s the support that they give... accompanying the family member to the clinic and kind of making it normal, be a normal part of the family” Stakeholder 1013

**Table 3.** Breakdown of Emotional Support Descriptions (n=59)

Subcodes		Description	Illustrative Quotes
Compassion and affection	Acceptance	Families create a space where ALWH do not feel judged or discriminated against	“If they create an environment which is nondiscriminatory, and they support you socially and otherwise... so I think that's support.” Stakeholder 1007
	Expressing interest in well-being	Families demonstrate care and interest in the ALWH’s emotional well-being and their care management	“He is interested to go everywhere alone because it got to him... [I said] “I am your mother and I am everything to you. So, I want you, even when you have a problem, to be able to talk to me and not be afraid... So, you can talk and chat with me.”” Caregiver 2018
Motivation from encouragement		Families encourage ALWH to continue treatment and remain hopeful	“It can make it easier like, you can like, also encourage me to take my treatment, also encourage me like, to eat a healthy and balanced life.” Stakeholder 1014

**Table 4.** Breakdown of Informational Support Descriptions (n=59)

Subcodes		Description	Illustrative Quotes
HIV Education	HIV management	Families explain how to take treatment, how to be responsible for HIV management, and other lifestyle suggestions	“[families] are aware of the side effects and know what to do with these side effects, being a treatment buddy to your child” Stakeholder 1012

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