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Understanding the support needs of caregivers of adolescents living with HIV who self-harm by understanding their role strain and role conflict experiences in Nakawa division, Kampala

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A research project submitted to Van Hall Larenstein, University of Applied science in partial fulfilment of the requirement for the degree of master's in management of Development, specialisation social Inclusion, gender and Youth

By

Allen Kyendikuwa

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Acknowledgement

Foremost, I give God the glory for having brought me this far in life.

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LIST OF ABBREVIATIONS

WHO	World health organisation
ALHIV	Adolescents living with HIV
UNYPA	Uganda network of people living with HIV
Y+ GLOBAL	Global Network of people living with HIV
UNAIDS	The Joint United Nations Programme on HIV/AIDS
HIV	Human immunodeficiency virus
AIDS	Acquired immunodeficiency syndrome
YPLHIV	Young people living with HIV
UNHCR	United Nations High Commissioner for Refugees

ABSTRACT:

Introduction:

This study was commissioned by the Global network of young people living with HIV (Y+ Global). The research will guide on how best Y+ Global can cumulate on the work that the organisation has initiated with UNYPA in supporting ALHIV who self-harm through supporting their caregivers.

Objective:

The objective of the research is to understand the care needs of caregivers to adolescents living with HIV who self-harm and provide a baseline study for Y+ Global through understanding the factors that stimulate role conflict and role strain for caregivers to adolescents living with HIV who self-harm.

Method:

The theory of role strain was tested in this research. The data was collected in three different phases: 20 caregivers of ALHIV who self-harm were selected with reference from the 40 Adolescents that UNYPA supports. The caregivers were provided with diaries and phones to record experiences in their days that cause role strains and conflict while looking after the adolescents. The recording was done within 30 days at any time or day of convenience. Structured interviews followed to input or follow up on any information and gaps missing from the diaries. Then 5 key informants were interviewed to give an expert opinion on the different aspects of the roles strains of caregivers.

Conclusion:

Caregivers of ALHIV who self-harm experience different role strains and role conflicts at the different stages of caregiving; They arise from the different roles that come with multiple responsibilities for example, a mother is a daughter to someone, a sister to someone, an employee to someone and a care giver to the adolescent. In all that capacity, she is still expected to fulfil those roles and satisfy everyone. Supporting the family financially, being present to look after the Adolescent who self-Harms, have fun with the ALHIV who self-harms ensuring that they are happy, being supportive while giving love and care gently, giving emotional support, providing guidance when needed, be present at work every day and on time. Due to the challenges in balancing the roles, caregivers find themselves at crossroads with roles conflicting with each other. For example, co-dependency of adolescents conflicts with the time constraints on economic work availability and performance for the caregivers, conflicts of having to choose self-love for the caregivers without hurting the ALHIV who self-harms, the results from the research have further proven William J. Goode's role strain theory. Due to the many challenges and the different responsibilities that the caregivers have to play, their ability to effectively and efficiently accomplish all of the tasks diminishes. This is because of the effects that impact ALHIV who self-harm are synonymous to the role conflict, strain and burden of the caregiver.

KEYWORDS: SELF-HARM, ADOLESCENTS, CAREGIVERS, HIV.

Chapter 1. INTRODUCTION

This paper is a thesis for a research study done to understand the role strain and role conflict of caregivers of ALHIV Who self-harm.

It is estimated that more than half of new HIV infections worldwide occur among young people of 15-24 years and up to a third of people living with HIV/AIDS are 25 years or younger. Young people in sub-Saharan Africa are disproportionally affected by the HIV/AIDS. The Uganda population-based HIV impact assessment indicated that HIV prevalence is nearly three times higher in young Ugandans aged 20-24 compared to those aged 15-19. HIV prevalence is almost three times higher among females than males aged 15 to 24 Nanyonjo et.al (2020) According to (UNAIDS, 2019) Approximately 1,500,000 people are living with HIV in Uganda with a prevalence rate of 6.2%. The average number of adolescents aged 10-19 living with HIV IS 100,000 (79,000-130,000), (UNAIDS,2019)

According to a study done in 40 countries all over the world by Gilles et.al (2018), 17% of the young people will self-harm themselves in their lifetime. The average age of the first incidence is 13 years and 45% use cutting as their method of self-harm. In Uganda, 6% of the population have harmed themselves (Kampala mental health clinic, 2020) Self-harm is recognised among? Adolescents especially in the mental health populations.

From my work experience as a programmer on HIV related programmes with both Y+ Global and CYSRA-Uganda, many cases go unreported as mental health is not a topic openly discussed in many communities in Uganda and Kampala in particular. Self-harm is culturally acceptable in some regions of the country as it is used for traditional treatments and initiations. In a setting like this, several cases will go unregistered which keeps the official numbers low.

Although self-harm is different from attempted suicide, they are closely related and studies show that people who have inflicted self-harm are three times more likely to attempt suicide (the recovery village, 2020). Adolescents living with HIV in Uganda live in life threatening conditions such as poverty and stigmatization that are a great drivers to self-harm (AGENDA, 2020). However, the available data around self-harm is mostly based on the UK statistics and the global north which calls for the need for an improved understanding of the cases of self-harm among adolescents living with HIV in Nakawa division, Kampala district.

In a presentation by WHO, 2019, constant illnesses and chronic diseases like HIV/AIDs are mentioned as a risk factor to self-harm among adolescents. Adolescents living with HIV self-harm for different reasons but the most common one is to deal with the life challenges they face. For adolescents living with HIV, there are other personal and social challenges that they must cope with such as stigma, pill burden and discrimination from important community engagements like

schools and marriages. Exclusion from such activities makes coping hard for ALHIV as they are in an explorative stage. The adolescents then resort to self-harm.

According to the royal college of psychiatrists (2019), self-harm is done by adolescents who need to stay in control whenever they feel helpless and trapped. In other cases, for adolescents who are not able to speak up in times of anger resort to self-harm to relieve the inbuilt anger and trauma or abuse, self-harm is also a means of punishing one's self when there are feelings of guilt or when a person wants to connect to the world and feel alive. For other adolescents, self-harm is a means to suicide when they are tired of living due to life challenges.

There is an additional risk for adolescents who self-harm as they usually share sharp objects and hence risk the spread of HIV within their social groups.

More than often, the adolescents who self-harm seek help from their families or people who look after them after an episode of self-harm rather than before (Arbuthnott and Lewis 2015). Arbuthnott adds that parents may be valuable members of the Adolescent's care as they spend much time with the adolescents. The parents are able to predict risk and triggers that cause ALHIV to self-harm. When a parent is vigilant, they support to alert health workers for quicker interventions.

With Support from Y+ Global, Uganda network of young people living with HIV (UNYPA) supports 40 young people living with HIV who self-harm. The adolescents and young people stay in the different divisions of Kampala city. Under support from UNYPA, the adolescents are supported through peer support groups to educate them and build their capacity for resilience. To successfully participate in the activities, the adolescents receive care and support from their family members, friends and professional care givers who help them to live meaningful and healthier lives. The project aims to improve the lives of ALHIV through improving their mental health and wellbeing. While carrying out the project, the organisation was constricted by the issues that arise from caregivers such as the inability for caregivers to understand the needs of the adolescents. The Adolescents were asked to fill in a questionnaire that explained the needs they have starting from most immediate to general needs. The immediate need they mentioned included: support to adhere, access to essential medicines including HIV medicines, access to mental health support and nutritional supplements.

Out of the 40 young people engaged, 25 reported to have self-harmed especially the first days when they discovered their HIV Status (UNYPA, 2019). According to Vreeman (2017) the need for a better understanding of mental health is especially important when its assessment and treatment are compounded by other comorbidities. Adolescents living with HIV may face an increased burden of mental and behavioural health disorders which leads to self-harm. But even with evidence like this above, there is still very limited research on the needs of care takers of ALHIV who self-harm. Being the main caregiver to an ALHIV comes with unique challenges such as stress, limited social interaction, reduced economic productivity (Moudatsou et.al,2021) all of which contribute to poor health outcomes of both caregiver and the ALHIV who self-harm. Y+ Global supports the ALHIV through the local partner Uganda network of young people living with HIV and hence the ALHIV have identified the need to engage the caregivers to get a better

support system. Y+ Global wishes to continue collaborating with the local partners to improve on the economic and social ability for caregivers to support ALHIV who self-harm.

The interest in supporting caregivers is because they play different roles that come with different expectations. Caregivers ALHIV who self-harm to attend the organisation's quarterly meetings, picking medicines from the respective health centres especially when the adolescents are in school, giving reminders to the adolescents to swallow medicines, clean their wounds, provide basic needs like food, security and other basic needs including, counselling and support when and if the conditions relapse.

COMMISIONER: GLOBAL NETWORK OF YOUNG PEOPLE LIVING WITH HIV (Y+ GLOBAL)

Y+ Global began as a programme of the Global Network of People Living with HIV (GNP+) in 2012 until it evolved into an independent organisation with its leadership, staff team and strategy. GNP+ continued to provide technical support and mentorship to the Y+ Global team to strengthen its operational capacity as a youth-led organisation. With the full backing of GNP+ towards our goal of

Independence, Y+ Global was successfully registered in the Netherlands and changed its headquarters from Cape Town to Amsterdam in 2021.

Y+ Global is an advocacy biased organisation that works to support young people living with HIV in all their diversity through local, regional and national networks that work with Young People Living with HIV across the globe to improve their life. The organisation works with partners in communities to provide skills and knowledge that promotes economic advancement of their lives. Currently the social Aid fund a project funded by UNAIDS supports YPLHIV in Eswatini, Zambia, Nigeria, Zimbabwe to support poultry and gardening for young people.

ASPIRATION:

Y+ Global aspires to develop a Global Network of Young People Living with HIV to serve both the Young People Living with HIV and the interests of the wider communities of people who support YPLHIV globally.

The study to understand the needs of caregivers of ALHIV who self-harm will contribute to strategic Goal 1: Lead on research paper: mental health strains among people who provide Peer 2 Peer support and strategic Goal 2: Involvement in Research & Development which will feed into the capacity building projects of the organisation.

PROBLEM STATEMENT:

Y+ Global has worked with young people living with HIV in all their diversity. There are different programmes that focus on the young people for example: HER Voice Fund focuses on the sexual reproductive health of Adolescent girls and young women in Sub-Saharan Africa, 4Youth focuses on the Networks of young people living with HIV in Eastern Europe and South America, READY+ works with networks of young people living with HIV in sub-Saharan Africa.

Self-harm is common and associated with adverse outcomes especially in the lives of adolescents and young people living with HIV. Research about the risk factors for self-harm has informed the field with regard to clinical interventions that should be provided for young people who engage in self-harm. The available studies lack an in-depth elaboration on the possible triggers that cause the urge for self-harm. There is little knowledge about what techniques young people or their caregivers find helpful to deal with urges to self-harm when they occur. (Hetrick 2020). According to Cavazos-Rehg (2020) adolescents living with HIV in Uganda are impacted by poverty and face a number of health and social challenges including access to medication, health complications, and social stigma which may contribute to self-harm. These same challenges are passed onto the care takers, children and relatives of the adolescents who self-injure.

This research will act as a baseline study (please see page 22 for indicators) for my commissioner Y+ Global in their quest to understand the support needs of caregivers of adolescents living with HIV who self-harm by understanding the role strain and role conflict experiences.

RESEARCH QUESTION:

What are the role strain and role conflict experiences for caregivers of adolescents living with HIV who self-harm in Nakawa division Kampala district, Uganda?

SUB-QUESTIONS:

1. What are the different roles of care givers of adolescents living with HIV who self-harm?
2. What enables caregivers to support adolescents living with HIV who self-harm?
3. What challenges are faced by caregivers of adolescents living with HIV who self-harm?
4. What are the support needs for care givers of adolescents living with HIV who self-harm?

OBJECTIVE:

The objective of the research is to understand the care needs of caregivers to adolescents living with HIV who self-harm and provide a baseline study for Y+ Global through understanding the factors that stimulate role conflict and role strain for caregivers to adolescents living with HIV who self-harm.

Chapter 2. LITERATURE REVIEW:

This chapter contains secondary information from the desk review. It contains information from the work done by researchers in relation to the topic of adolescents living with HIV who self-harm. The information in this chapter is drawn from journals, books, media as retrieved from google scholar and other search engines. The chapter will explain further the definition of the important terms used in the document and enlightens on the burden of self-harm among adolescents living with HIV.

According to WHO(2016), Self-harm is an act with non-fatal outcome in which an individual deliberately initiates a non-habitual behaviour that, without intervention from others, will cause self-harm, or deliberately ingests a substance in excess of the prescribed dosage, and which is aimed at realizing changes that the person desires via the actual or expected physical consequences. However, Quarshie E.N.B et.al (2020), mentions that there is limited information about self-harm by young people in sub-Saharan Africa in comparison to the high income countries where self-harm is a recognised problem that is associated with a number of poor outcomes including death. In my view, the lack of data about self-harm in adolescents in Sub-Saharan Africa doesn't dismiss the fact that Adolescents face mental health related issues that lead to self-harm.

For the purpose of this research, self-harm is defined as self-inflicted bodily harm like poisoning, or injury by an individual to bring about desired changes with non-fatal intent or outcomes.

John Hopkins medicine (2018) define a caregiver as a person who tends to the needs or concerns of a person with short or long-term limitations due to illness, injury or disability. Caregivers of adolescents living with HIV who self-harm are concerned with their needs and abilities to take control of their environment and deal with stressful situations (Moudatsou et.al,2021). In addition, Muliira (2018) added that family caregivers assume roles without prior experience. They do lack the knowledge and skills required to look after the patients. Moudatsou further elaborates that the quickly acquired multiple roles and responsibilities of the caregivers impact on their self-esteem, coping capacity and problem solving ability. From another perspective, Cassels et.al (2018) suggests that the poor support of family members due to role conflict also contributes highly to the onset and increase in self-harm for ALHIV.

Caregivers experience stress more frequently due to multiple reasons such as, fear for the loss of their loved one, concern about the suffering of the family member and the additional demand of providing emotional and economic support (Alder and Page 2008). Moudatsou 2021 further mentions that the chronic stress experienced by caregivers who have taken on the responsibility to look after the dependent loved ones affects them health in three different ways. The caregivers turn to unhealthy practices like smoking, use of medicine frequently and inability to seek health

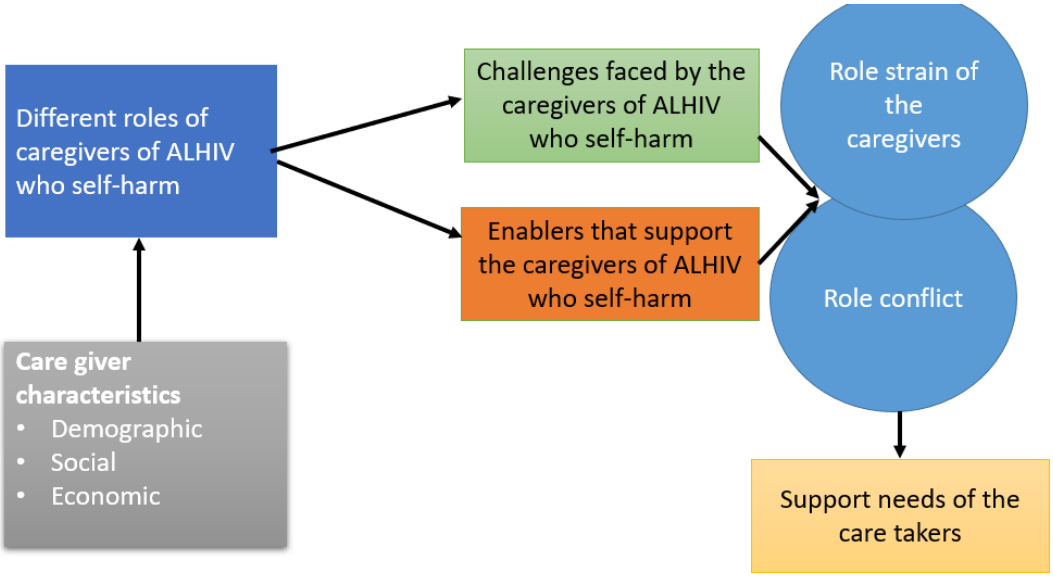
services to address their own needs. This is associated to affecting their immune systems and hence reducing on the quality of their health. However, Lindgren et.al (2010) found that parents who do not participate in the caregiving of their adolescents feel left out and hence looking after the children is satisfying. In the first two accounts, it is shown that fear and stress of looking after ALHIV who self-harm affects the mental wellbeing of the caregivers and puts them in a position to be dependant to extra support as well while not giving care to the ALHIV is also a cause of stress to some parents.

A Significant percentage of caregivers experience change in working environments (Adler and Page 2008). This includes quitting jobs, interruption in work or reducing hours at work in order to look after the ALHIV who self-harm. The national sciences engineering medicines (2016) mentions that the change in working conditions of the caregivers reduces the family income but also encourage on saving of the incomes that would have been spent on hiring formal health support. Both researchers mention the financial burden which may also contribute to stress as the caregivers are not able to financially provide the basic needs to the ALHIV who self-harm.

CONCEPTUAL FRAMEWORK:

This study will be guided by a framework that is adapted from William J. Goode's (1960) role strain theory. Role Strain Theory is a widely accepted psychological theory that in previous research (e.g., Hayman et al., 2019) has been applied to identify meaningful relationships between psychological and physical well-being and perceptions and experiences of demands placed on the elite performer when combining educational and Role Strain Theory and Elite Adolescent Golf Development sporting commitments in adolescence. Chistopolskaya (2020) tested the theory on a study called "the moderating role of social support". The theory gives a perspective how straining the role of a person in a society can create poor delivery outcomes in performing that role which relates to the researcher's study, that seeks to understand the support needs of caregivers of adolescents who self-harm, their role strains, challenges, opportunities and how best they can be supported to better be involved in the lives of the adolescents who self-harm. The theory of role strain takes into consideration the perspectives from the caregivers and how they might conflict with the needs of the adolescents and hence it is a model well suited to understand the needs of the caregivers.

Figure 1: CONCEPTUAL FRAMEWORK



Source: Author, (2021)

The theory of role strain suggests that societies are made up of role relationships, and approaches both social action and social structure through the notion of "role strain," the felt difficulty in fulfilling role obligations (ASA,1960).

In order to access the needs of the care givers, there is need to understand the care giver characteristics including their demography, social dimensions and Economic potential as displayed in figure above. The above characteristics explain the vulnerabilities of the care giver and describe the nature of support needed to improve the lives of the adolescents who self-harm.

As a second step, there is need to understand the level of support that the care givers give to the adolescents who self-harm. This includes the quality, capacity and acceptance. At the second step there is need to describe the various social, physical and emotional roles (onklink,2020)of the different caregivers and to understand how the roles strain and challenge the care giver thereby leading to role conflict between the external caregivers such as health workers, teachers and the primary care givers that stay at home with the ALHIV who self-harm. After identifying all the process, then the needs of the caretakers will be identified.

DEFINING THE KEY CONCEPTS:

Self-Harm: Self-harm is “An act with non-fatal outcome in which an individual deliberately initiates a non-habitual behaviour that, without intervention from others, will cause self-harm, or deliberately ingests a substance in excess of the prescribed dosage, and which is aimed at realizing changes that the person desires via the actual or expected physical consequences” (WHO,2016 pg,9). For the purpose of this research, self-harm is defined as self-inflicted bodily harm like

poisoning, or injury by an individual to bring about desired changes with non-fatal intent or outcomes.

Adolescents: the WHO (2020) defines Adolescents as those between 10-19 years. This means that most adolescents are put into the category defined for children according to the convention of rights of children (UNHCR, 1990) as a person under the age of 18. There are other terms that are interchangeably used with the term adolescence: such as young people who are categorised as 10-24years and youth who are categorised from 15-24 years. For the purpose of this research, Adolescents are between ages of 14-19 years and are living with HIV.

Caregivers: According to John Hopkins medicine (2021), a caregiver is a person who tends to the needs or concerns of a person with short or long-term limitations due to illness, injury or disability. In another account by Moudatsau(2021), a caregiver is anyone who provides support to a person to meet their daily need or companionship. There are two categories of caregivers (Moudatsau, 2021), formal caregivers (a person who is paid to care for someone) and informal caregivers (family, relatives, friends, neighbours). A caregiver is a person who is responsible for direct care, protection and supervision of activities done by Adolescents living with HIV. Caretakers can be school teachers, parents, guardians or the social workers in the community.

Role strain: is the felt difficulty in fulfilling a role (Thoughtco, 2020). Role strain occurs when people experience stress in their role. According to Wehner.L.E (2015) role strain is the palpable difficulty of self to fulfil role demands emitting from others. It can be a reaction to multiple and competing expectations. Caregivers of adolescents who self-harm have different roles beyond looking after the adolescents which causes strains.

Role conflict: is when two or more roles are at odd with each other. Gordon,J.R et.al(2011) defines role conflict as a bidirectional construct in which work interferes with care giving and care giving interferes with work. Role conflict occurs when people face role demands that are mutually exclusive and neither of them can be released.

Caregiver needs: A need is the requirement of individuals or communities to enable them achieve, maintain or restore an acceptable level of social independence or quality of life (Asadi-Lari, 2003). According to Moudatsau(2021), a need is a complex concept which includes a range of issues related to the wider social and economic environment in which the person lives. They include, health services, housing, companionship, food, education and others.

Caregiver needs are therefore defined as requirements of individuals who provide support to adolescents living with HIV who self-harm to enhance their capacity to achieve an acceptable level of independence and improved quality of life.

Quality of support: support is to give encouragement to someone or something because you want to see him or her succeed. It also means to help someone emotionally or in a practical way.

Quality means how good or how bad something is.

Quality of support is therefore the level (poor or good) of economic, emotional or practical encouragement or help given to adolescents living with HIV who self-harm to help them achieve a degree of acceptable independence and improve their lives.

Capacity of support: , capacity is someone's ability to do something. Capacity includes power and capabilities (economic, social and physical) of a person.

Capacity of support there is the caregiver's ability, potential, power and capability to give economic, emotional and or practical encouragement or help to adolescents living with HIV who self-harm to help them achieve a degree of acceptable independence and improve their lives.

Acceptance of support: Acceptance is the act of agreeing to an offer, plan or invitation However, this doesn't guarantee that a person wants or supports whatever it is they are accepting (Bruneau, 2017).

Acceptance of support is the active process by which adolescents living with HIV who self-harm agree to the emotional, physical or economic support given to them by the caregivers.

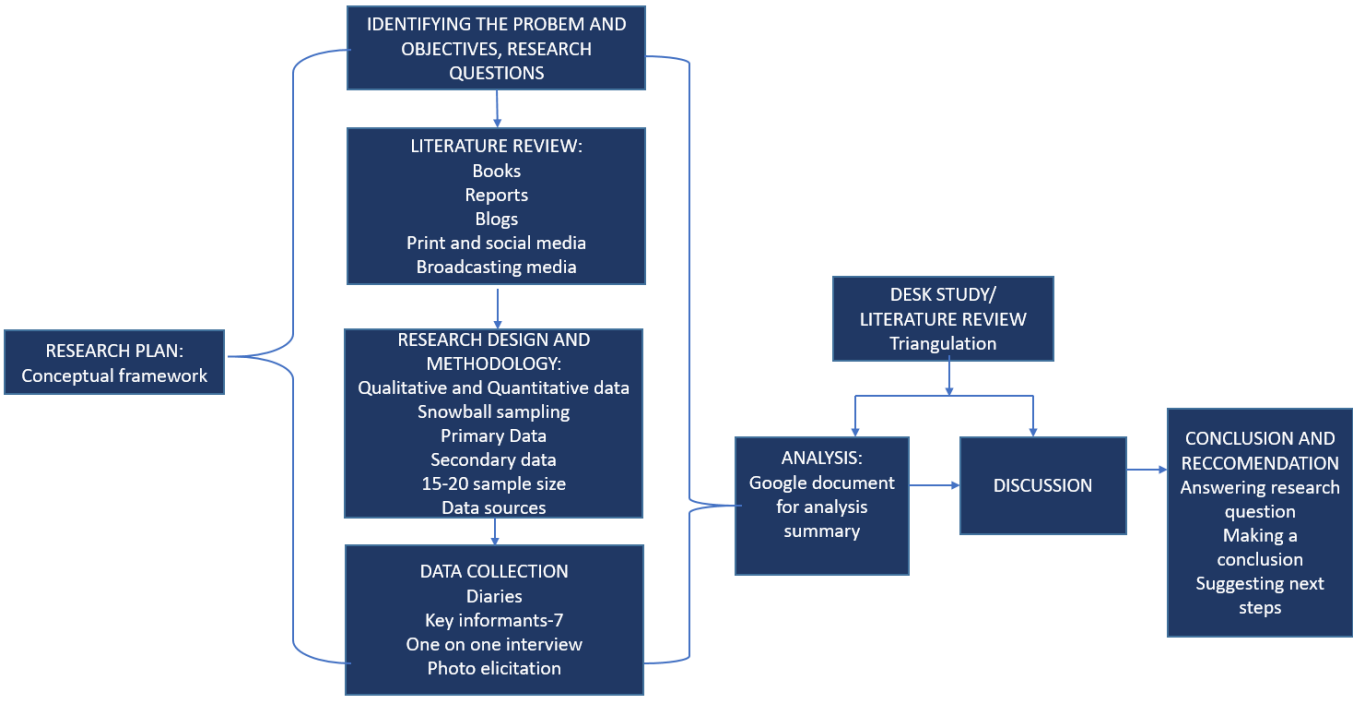
METHODOLOGY:

This chapter describes the specific procedures and techniques that were used to select topic, identify, select, and analyse information of the research. The chapter includes the research area, the methods that were used for data collection, the number of respondents, processes that were used to analyse data, ethical considerations and limitations of the research.

RESEARCH DESIGN:

Below is a figure that illustrates the methods and techniques used by the researcher to carry out the research on the role strains and role conflicts experiences of caregivers of adolescents living with HIV who self -harm in Nakawa division, Kampala district, Uganda..

Figure 2: RESEARCH DESIGN



CONTRIBUTION OF THE STUDY:

The selection of the topic of study was discussed with the programmes manager at the organisation. The programme manager suggested that I should select one of the three neglected topics in respect to young people living with HIV. Topic one was married and divorced under 20, self-harm among young people living with HIV and pregnancies among young people living with HIV during COVID-19. The programme manager thought that it is important to understand any aspect of the dynamics as there was not much work being done around the topic. She suggested that it would be a base study to guide project implementation of the work for the organisation. When I selected self-harm because it is related to mental health, a subject I am passionate about, shec suggested that I reach out to UNYPA as they were already doing activities with the young people who self-harm. Self-harm is a topic not covered in Uganda as there is no or limited data around the topic in regard to adolescents and or young people living with HIV. While conducting the desk review, data suggested that the rate of self-harm is low in the country. However, the research findings found an overwhelming number of ALHIV who self-harm. The research will contribute to the work of organisations that support adolescents who self-harm.

The researcher worked with two research assistants:

Ms. Nalugo Sharifa

Ms Nalugo is a trained para-social worker, counsellor and peer educator at UNYPA and international community of women living with HIV east Africa. She has collected data for the 3Es research study that was looking at Empowering Equipping Equality for young people living with HIV, the 4Ms network research that looking at equipping pregnant mothers with post antenatal information and participated in the ABCD research study that is looking at the mental well-being of a pregnant adolescents and the young mothers.

Ms. Akumu Leticia

Ms Leticia Akumu holds a certificate in early childhood studies (ECD). She has been part of the telomere study on Ugandan youth who perinatally acquired HIV.(youth study coordinator at the Makerere university John Hopkins university research centre , she has also collected data for the REACH study (reversing the epidermic In Africa with choices in HIV prevention) a trial that sought to understand the HIV prevention needs and preferences of adolescent girls and young women in sub Saharan Africa at the Makerere university John Hopkins university research centre as the youth peer educator.

I requested the research assistants to acquire the UNICEF web based training on ethics and human data handling.

SELECTION OF THE PARTICIPANTS:

The participants who were selected to take part in this study were listed by the ALHIV supported by UNYPA as caregivers of ALHIV who self-harm. They were selected from the existing database by recommendation from the project officer responsible for the project. They were selected

because they are still actively self-harming and are still in the process to reduce on the harm. After selection, the research assistants requested the ALHIV to take them to their homes. The adolescents agreed and then the research assistants went to the area to explain the details of the research to the selected participants. They supported them to sign the consent forms and gave them the books and cell phones for diary recording. The participants were welcoming and they planned four different days to interview 5 participants

DESCRIPTION OF THE AREA:

The study was conducted in Nakawa division, Kampala district the capital city of Uganda. Kampala is located in the central part of the country with a population of 1,650,800 as of 2019 (KCCA,2019). It is made up of 5 divisions namely, Makindye, Nakawa, Kawempe, Kampala central and Rubaga. The prevalence of HIV in Kampala is 7.1% compared to the country's 6.2% (KCCA, 2019) with an estimated 6.9% of the people living with HIV.

Kampala is also the most populated district and has two government facilitated hospitals that work with mental health they are: Butabiika hospital in Luzira and Bbosa mental health centre in Mulago hospital.

MAP OF KAMPALA SHOWING THE FIVE DIVISIONS.

Kampala is currently divided into 5 urban Divisions namely: Central, Kawempe, Lubaga, Makindye and Nakawa Divisions. There are the five Division Urban Councils which are headed by the Division Chairpersons who are also known as the Division Mayors. The focus of the study was in Nakawa division which is marked yellow on the map below. The proposal however, had planned that the research be done in Makindye division but the lockdown was made effective and people migrated from Makindye to their home villages as it would be safer to access food in villages than in Makindye. Together with young people at UNYPA, the researcher was directed to Nakawa division where UNYPA is supporting a few ALHIV who self-harm. Most of the respondents in Nakawa were found in Naguru go down which is an informal settlement where many adolescents and young people use drugs.

Figure 3: MAP OF KAMPALA DISTRICT

STRATEGY:

A case study was the selected strategy for the research. 20 caregivers were given books and pens to work on diaries and those who cannot read and write were given phones to record the information that they experience in a day. The 20 caregivers were also interviewed and two unique cases were selected to be referred to more as their diaries were written with good detail. The participants were given the details of the research and asked to consent. All of the participants requested to participate agreed to the process. For easy identification, the researcher will allocate pseudo names to the two participants of the study. The two caregivers who were selected include:

Nankinga is a stepmother who cares for an adolescent (17 years old) who gave birth at 14 years to her first born. After child birth, the adolescent started self-harm. She got pregnant in the year after and she now has two children, and continues to self-harm

Nalugo is a single mother and they do not know the where abouts of the father to the Adolescent who self-harms.

The cases were selected to explain, describe and explore the difference in the lives of care givers to adolescents who self harm who are in more complicated situations than their peers.

RESEARCH APPROACH:

Qualitative approach was applied as the data needed an in-depth and unique experience for all the participants. In addition, the sensitivity of the topic of research, the need to gain rapport and trust during the interview process and the limited information available regarding the topic of study required an approach that is in person with minimal participants at a time.

DATA COLLECTION AND SAMPLING METHODS:

The research employed multiple data collection methods and tools to gather the relevant information. The study utilised both primary and secondary data sources to enable triangulation and validation of the data collected.

The participants were selected by age of the adolescent under their care (15 – 19 years), the period of time they have been under the caregiver's care (not less than six months). The selected participants were 12 women and 8 men.

DESK REVIEW

A literature review was conducted to get background information and to triangulate the data that was received from the primary sources. The desk review supported in integrating findings and perspectives of similar researches done previously. Desk review helped in validating data through comparing the data with the already existing data done by the different researchers. The search engines that were used include GreenI, google scholar and science direct.

SEMI STRUCTURED INTERVIEWS:

With support from two research assistants, the researcher conducted 20 interviews with 20 participants who are all caregivers of ALHIV who self-harm. The researcher was connected through zoom using the phones of the research assistants. 5 interviews were conducted each day until the researcher collected all the information she required.

The two research assistants supported in writing down the information, recording as the participants didn't feel comfortable being recorded on zoom. The research assistants also followed up to remind the participants amount the diaries and the phone recorders that they had.

Semi structured interviews were used and a sample is attached in the appendix, the researcher and the research assistants followed the conversation to inquire further about different information that the participants were sharing.

KEY INFORMANTS:

Five key informants were selected to be interviewed and shared expert knowledge on what enables formal caregivers to support adolescents living with HIV who self-harm. An email was written to invite the key respondents to provide a suitable time that would support the interview. The researcher then set up a calendar invite and shared a zoom link for the key informants to join. The calls were recorded with consent from all the participants. Initially, the researcher had planned to interview community leaders but since the lockdown delayed the process and complicated the possibilities of local leader interviews, the researcher decided to work with the formal and experienced informants in the line of treatment and care for ALHIV who self-harm. The five key interviewees were:

Professor Kinyanda Eugene:

Professor Eugene Kinyanda is a senior investigator scientist and head of the mental health project at the Medical Research Council /Uganda Virus Research Institute on AIDS. Over the last six years he has undertaken research into the psychiatric and psychosocial complications of HIV/AIDS among adults.

Ms Ayabale Erone

She is a junior investigator at Butabiika national referral hospital. Erone is also a clinical psychologist at Butabiika Regional referral hospital. She has 3 years' experience taking care of adolescents and young people who use drugs, self-harm and those with different mental health challenges.

Dr. Rujumba Joseph

Dr. Rujumba is currently a Lecturer in the Department of Paediatrics and Child Health, School of Medicine, Makerere University. He provides medical social work services at the adolescent clinic and paediatric wards Mulago National Referral Hospital. He is part of the team that co-founded and runs the adolescent clinic at Mulago hospital.

Ms Esther Kangave:

She is a counsellor at Baylor college of medicine children's foundation Uganda with over 30 years' experience in the field of HIV and adolescents. The clinic supports children and adolescents living with HIV.

Mr. Bukenya Dennis:

He is the former manager at Naguru teenage health and information centre. He is a social worker and a seasoned Adolescent/Youth health and development practitioner that has contributed towards improving the lives of young people and youth around the world for over 15 years.

PERSONAL DIARY METHOD:

This method was selected because it provides a detailed account of the day to day events that happen in the lives of the caregivers. At the beginning of the research, the lead researcher called the participants with support from the research assistants. The researcher introduced herself and the research, why it was being done, how it would benefit the participants and the researcher requested the care givers to share an account of their day especially the special days that have unique events. They were to write or record any number of desired diaries with 30 days at their own pace. They were requested to write their different experiences depending on how they perceive the different times within 30 days. The caregivers were given books and pens by the research assistants the research assistants labelled the books for convenience. To support the caregivers who were not able to write, smartphones were provided to record voices as part of their diaries instead of writing down. They were requested to take photos if they felt comfortable with sharing photographic information.

The research assistants collected the diaries and shared them with the researcher at the end of the 30 days. The research assistants collected back 13 books all the 7 cell phones to retrieve the recordings and images. However, only 5 books had very comprehensive and detailed information. The 8 books were presented with only a few written lines on different pages. All the diaries had specific dates for reference including the diaries that had a few sentence. The participants were however not comfortable taking photos. They were not comfortable and rejected any photo taking except one young man who agreed to take a back view photo. Three of the seven phones had clear and comprehensive recordings although the recordings missed the dates. The diary method supported the researcher to answer the three sub questions of the research on the different roles of care givers, challenges faced by caregivers of ALHIV who self-harm and the enabling factors that support the caregivers of ALHIV who self-harm. The diary method gave opportunity for the respondents to record their challenges, feelings, positive and negative experiences each day in a time convenient to them. The diaries also supported the researcher to have a relatable feel of physical presence in the environment. This is because the researcher was not able to physically collect the data, it was important for her to have empathy and understand how other people live within those environments.

DATA ANALYSIS METHOD

The research assistants transcribed the 20 interviews and shared the 20 transcripts with the researcher with the voice recordings to ensure that the researcher did not miss any information. The transcribed pages were labelled form 1 to 20 and the recordings were labelled the same way in correspondence. The research assistants also transcribed the diaries into English and also took photos of the originally written diaries The data was analysed in google tables and excel work sheets. A table was created with the different aspects to be analysed, the researcher incorporated the data every day that they had interviews and the researcher would probe for more data required in the different aspects that were important for the study. The excel worksheet was used to compute the nominal data like age of the adolescents, age of the caregivers. The excel was

also used to compute the period of time that the caregiver has been responsible for the adolescent as the participant selection was based on caregivers who had been responsible for the adolescent for over six months. A conceptualised table was sketched to support with data analysis. Sample of the table is attached below:

Table 1: SAMPLE TABLE USED FOR ANALYSIS

AGE	RELATIONSHIP TO YP	AGE OF THE CHILD	HOW LONG HAS THE YP BEEN UNDER CAREGIVERS GUIDANCE SINCE SINCE SELF HARM ONSET	PERSONAL IMAGE	DIFFERENT ROLES OF CAREGIVERS	ROLE EXPECTATIONS	ROLE COMFLICT	ROLE STRAIN

DATA VALIDITY AND RELIABILITY:

Constantly, the researcher checked the methodological coherence to ensure that the research questions are congruent with the methodologies. The researcher changed different questions and added a few others like age of onset for self-harm. The changes were done after analysing the first set of data of the first five interviews. This is so because the researcher found the need to mention the age of onset of self-harm. The addition of the question provided more information that supported the research to understand the triggers of self-harm for the adolescents and it was important for the researcher because the researcher learnt that the caregivers are able to notice the triggers and take more precaution with the adolescent.

The collecting and analysing of the data co-currently supported mutual interaction of what is known and what needs to be added into the research. In this case, the individual diaries complemented the interviews

The Key informant interviews are also transcribed and the researcher has all the 5 copies available with her. They were emailed back to the key informants for a final review and sign off before they were added to the results section to support validation on issues that were misquoted or misrepresented. Fortunately, the key informants agreed that their views were not misrepresented and that the information in this aspect was accurate.

Finally, the researcher used a draft benchmark to cross check whether the indicators written to measure the baseline were filled in accurately see reference of the table below:

Table 2: SAMPLE OF BASELINE BENCHMARK

	BASELINE VALUES			
Indicators	Overall	By age	By sex	Comments

Number of caregivers interviewed in Nakawa division	20	21-46	12 female 9 male	
Number of caregivers with the correct information about caring for ALHIV who self-harm	1	30	Male	He is a trained mental health nurse
Number of caregivers who have paid work	5	28 30 46 38 27	3 females 2 males	Due to COVID-19 this was hard to compute
Amount of time spent by care givers with the ALHIV who self-harm				Most of the time for all caregivers
Number of people under the care of the caregiver				Varying with household structure between 2 - 7 people
Degree to which ALHIV who self-harm are allowing to access support				The adolescents are open to receive support

ETHICS THAT WERE CONSIDERED

Confidentiality between the research assistants and the respondents. There were no requirements to give one's identifiable and traceable personal bio data except for one's gender.

Consent was sought to take photos, diaries or any other type of information collected. The research assistants took time to explain the details about the research, why it was being done,

how the information will be shared, to whom the information will be shared and how the respondents would benefit from the research.

The research assistants communicated to the respondents that the information will be used for academic purposes only.

Shared openness was promoted. The respondents were given opportunity to ask any questions at any point of the interview and they were reminded that they can withdraw consent if they no longer feel comfortable answering the questions or participating in the research.

LIMITATION OF THE RESEARCH

One of the major limitations was the second wave of COVID-19 that caused a lockdown in Uganda at the time of data collection(MOH, 2021). Particularly in the researcher's area of data collection, the SOPs were stringent because the area is in Kampala city the most affected area. COVID-19 is a disease caused by the newly discovered Coronavirus(WHO,2021)the disease hit the world in late 2019 starting from the Wuhan territory of China and by march 2020, It was declared a pandemic by the WHO(WHO,2020). Uganda was equally hit like the rest of the world and on 7th of June 2021, the ministry of health released a directive to the health workers informing them about the fatality of the second wave "this wave is more virulent and spreading faster than the previous wave we experienced" The letter followed a directive given by the president to go into a lock down on Sunday 6th June 2021(Reuters, 2021). The lockdown was extended with 42 more days after the end of the first lockdown and specifically, transport in Kampala, meeting a person who isn't from same household and curfew were emphasised. For the above reason, the community gathering is expelled and hence the research assistants were not able to bypass the travel restrictions.

The Lockdown impact delayed the data collection of the researcher. The researcher's methods of data collection were in chronological order which included waiting for the diaries to be collected before the interviews can take place. The researcher was only able to collect the interview data 2 weeks before the date of submission for the thesis.

The researcher had intended to collect data from Makindye division but the COVID-19 wave had disrupted communities and many people had shifted from their localities into their ancestral homes to ensure that they receive food as food is cheaper and more accessible in the villages as compared to the city. The researcher then changed her study to Nakawa division with support from the young research assistants and UNYPA

FINDINGS:

The chapter begins with a description of the different profiles of the caregivers, presents the findings from the interviews both the key informant interviews and the interviews findings from the 20 caregivers who participated in the research. It also has findings from the diaries that were collected from the research. The results are presented in the different themes of the conceptual framework including: profiles of the caregivers, the different roles that the caregivers perform,

the role expectations from the different roles, challenges, role conflict, role strain, enabling factors that support the caregivers, support needed by the caregivers:

PROFILES OF THE CAREGIVERS:

The caregivers involved in this research are aged from 21 to 46 years old. The majority of the caregivers are below 27 years old, the average age is 29.1 years. The caregivers are friends, accomplices and or just kind people who volunteer to take care of the ALHIV who self-harm. A few of the givers are directly related to the ALHIV who self-harm for example mothers, fathers and siblings. The researcher carried out interviews to get the information on profiles.

Many of the participants who are caregiving to people not related to them mentioned that the adolescents come from wealthy families and they ran away from their homes to come stay with their peers in the slum areas.

The profiles in table three below describe the different context of the caregivers who were interviewed in the process. However, the first two profiles are distinct because apart from HIV and self-harm, culture influences how people are treated in communities. The women who are unmarried and do not know the father to their children are called names and are shamed for not being married for knowing the father to their children. In addition, step mothers are labelled ruthless and it is almost impossible to convince a many Ugandans that there are good step mothers. The profiles of the two women below and their commitment to escort their adolescents to seek care caught my attention. The researcher requested the women to participate and share detailed information. The caregivers shared more details regarding their cases including one being a step parent caring for an adolescent mother (aged 17) who is living with HIV and self-harms with two babies both below 5 years. The other case selected is about a single mother who does not know the father of her adolescent and this is a reason for heavy stigma and name calling within her community and hence the researcher focused on in detail. Pseudo names of Nankinga and Nalugo will be used to identify the two cases henceforth.

Nankinga is a 32 year old step mother to the ALHIV who self-harms. She is the sole provider to the family (she sells snacks by the roadside in the evenings and washes clothes door to door), she is a mother to 3 children of her own, she looks after the children of the young person who self-harms, she looks after her grandmother, she is also living with HIV. The adolescent is 17 years old.

Nalugo is 46 years old, a single mother, unmarried and is not sure where the father of the child is. She manages tap water selling in the community, fetches water for other people and washes clothes whenever needed. The adolescent is 19 years old

Table 3: PROFILES OF THE CAREGIVERS

CAREGIVER RELATIONSHIP TO ALHIV	**DETAILS ABOUT THE CAREGIVER**	**Sex of the caregiver**	**Age of the adolescent**

Counsellor/nurse	30 years old, mental health nurse, has a girlfriend, works at butabika hospital, stays in a single room at hospital quarters	Male	19
Concerned person	28 years old, works in a car dealership, employs young men, he is an employee himself, he has a wife	Male	17
Cousin	Casual labourer, 24 years old, lives with the parents	Male	17
Aunt	27 years old, manages selling of tap water, she is a mother to four children below 10 years	Female	16
Friend	25 year old School teacher, no longer has a job due to COVID-19	Female	19
Employer	24 years old, married with children, an electrical technician	Male	19
Sister	Student, fitness fanatic, 25 years old, does not work	Female	15
boyfriend	24 years old, bricklayer, does not work since the onset of COVID-19, breadwinner in his home	Male	18
Friend	21 years old, religious and enjoys preaching the gospel. Song writer at church	Male	18
Older Brother	25 years old,an orphan, he has been taking care of his brother since they lost their parents. He helps at building sites whenever opportunity comes	Male	17
Mother	36 years old, market vendor but has not been working since COVID-19, lost her husband and has not healed from the tragedy,	Female	16
Paternal aunt	27 years old, stopped working since COVID-19 and only goes around the area looking for what to do to earn income	Female	17
Aunt	33 years old, manages the selling of tap water. The tap is owned by someone	Female	16
Younger sister	She is a house wife of 18 years. Her sister is 19 years old, has two little children and solely	Female	19

	depends on her husband for income.		
Mother	36 year old mother who used to be a factory worker before COVID-19.	Female	18
Concerned person	28 year old security officer. Works at night and rests during day, he has been working during day since COVID-19	Male	16
Mother	36 years old, cohabiting with the father, living with HIV. No longer works due to COVID-19	Female	19
Maternal Aunt	A 37 year old washes clothes in people's homes. She has children at her home	Female	16

All of the respondents live in one of the poorest areas in Kampala district. It is a slum with poor housing conditions, bad road conditions and the people who live in the area have limited access to incomes that promote access to quality social services including schools, hospitals and water.

Nakawa division is the name of the area of study however, many of the respondents were found in Naguru go down area. It is located next to a very high class residential area where most caregivers go to find low end work like washing clothes, cleaning houses, providing house security, being house helps, selling snacks by the roadside and cleaning the cars.

Seven of the caregivers disclosed their HIV positive status during the interview. These are the parents who mentioned that their children were perinatally infected. Most of the ALHIV who self-harm share sharp instruments like razor blades, knives and compasses found in school sets. This is where most of the adolescents acquired HIV.

Figure 4: PHOTO OF PART OF THE HOUSING IN THE CATCHMENT AREA

THE DIFFERENT ROLES OF THE CAREGIVERS:

According to the research findings, the roles of the caregivers differ from one person to another however depending on the relationship that the caregiver has with the ALHIV who self-harms, there are cross cutting roles that demand the same level of responsibility with every caregiver. The different roles for different people that surfaced during the research include: being a friend, being a parent, being a counsellor, being a cousin, being a teacher, being a nurse, being a concerned person, being an employer, being their child's nanny, being an uncle and being an aunt depending on the context of the person.

In the case of Nankinga for example, she is a mother, a grandmother to the two children to her step daughter, she is the financial backbone of the family, she is responsible for looking out for the step daughter's sexual life and health in general. She is a granddaughter as she was raised by her grandmother who she speaks about dearly. She also has to attend to her work in order to pay for fees. *"Their father doesn't have a job, so everything regarding their well-being and health is catered for by me"* ***(Nankinga, interview)***

Nalugo on the other hand is a single parent who serves dual roles and responsibilities, an employee and a worker. The life of all her children depends on her. Nalugo is a daughter to her mother and fetches water for the community

ROLE EXPECTATIONS:

The findings suggest that most of the caregivers share similar role expectations including financing the home, emotional support and availability, being compassionate and loving, reminding the young people who self-harm to take their medicines, counselling and guidance support and cooking meals for the ALHIV who self-harm although distinct depending on the individual. For all the different roles, there are expectations that come with it. The researcher found that:

Parents: parents constitute both the mothers and fathers that participated in the research. The care givers are expected to achieve certain role expectations which include providing for the family financially including providing all the basic needs in the home from clothing, shelter, food and paying for school dues. According to the respondents who identify as mothers: the mothers are mostly expected to be present in the child's lives regardless of their status of employment. Mothers are responsible for making sure that the adolescent does not self-harm and hence should be watching the time. A mother of one adolescent was quoted saying *"Ever since the child started self-harming I make sure she doesn't leave my site for a long while"**(mother, diary)*. The mother further mentioned that she even goes to school to pick the adolescent up because she is concerned that leaving her to walk alone might cause a relapse of harm. In an interview with Dr. Rujumba, he mentioned that the parents also play a crucial role in following the Adolescents to pick their medicines including ART and prescription drugs for mental health and in cases where the adolescents are not able to comprehend the situation and in places where they are minors, the parents are allowed to give consent on treatments or other decisions as required.

Sister or brother: most caregivers mentioned that they have siblings that they have obligations to. Particularly, the caregivers who are siblings mentioned that as part of their role, the attached expectation as ascribed by societyis to have fun with the sibling who self-harms including joining them for parties, hiding the truth from their parents because their parents do not live with them. One of the respondents mentioned that *"because I am her younger sister, she always wants me to go to the salon with her, take her out when I go with my friends and buy for her things outside the basic needs"*

Boyfriend/girlfriend: As a partner, the role expectations include, being supportive, loving, understanding and caring. The research found that partners have responsibility to be present and available for their partners who self-harm. ALHIV who self-harm expect this and not less. Partners who are caregivers mentioned that there is a lot of emotional dependency on them and that when they fall short, they risk the potential for a repetitive cycle of self-harm.

Nurse / Counsellor: According to the research findings, the participant who identified as a counsellor/ nurse mentioned that their role included giving emotional support especially when the ALHIV who self-harm are not able to be congruent with their immediate feelings about

something. The counsellor shared that the Adolescent started self-harm after the death of his mother and every time there is death around, it triggers his self-harm. In the same regard, when the adolescent does not have access to money, He refers to the death of his mother as the reason and lingers in what would have been only if his mother was still living. The nurse quotes *"sometimes I must carry him into my single roomed house that I share with my girlfriend in fear that if I left him behind, he will harm himself".* Ms. Ayebale the Key informant added that in regard to this role, there are expectations of cleaning the wounds, reminders to take medicines and ensuring that they eat on time

Worker or employee: As a worker, the caregiver mentioned that their employers expect them to be at work on time every day and in time for their daily routines or shifts in line with their allocated working hours which are usually from 8am until 5pm. One of the participants goes door to door washing clothes for people but because she is not able to leave the adolescent for a long time, she opts to carry clothes to her home. However, some clients are not comfortable with taking away their clothes and hence she has lost so many customers for that reason. She quoted *"I am not able to leave her alone for a long time, she easily gets irritated and that worries me all the time".*

Student: The caregiver who identified as a student mentioned that her role requires that she attends school every day and on time including passing her classes well. Since she enjoys working out at the gym, that is also an expectation she has to take care of in addition to the responsibility she has towards her little sister who self-harms.

CHALLENGES:

In relation to challenges faced by the caregivers, findings of the research show that the caregivers are challenged by the negative behavioural practices that their children participate in like theft. Most of the respondents agreed that the Adolescents are driven by drug abuse which influences their activities. Whenever they run out of the drugs, they do all they can to ensure that they receive them. The caregivers have found the need to have to use their money to buy these drugs to ensure that the ALHIV do not actually inflict harm on their bodies out of desperation. Three of the respondents mentioned that the adolescents steal a lot from them and from the community. One mother mentioned that the adolescent steals a lot of money as long as he has access to the money. *"He once stole the television and sold it out at a very cheap price. He used the money to buy drugs and he cut himself to use the drugs".* The mother further said that the theft makes it hard to progress financially as they continue to restock the items that have been stolen. In another account, a father of one of the adolescents mentioned that the young man was sent to prison due to theft, he had stolen a bicycle and was caught. He got tortured and he was not able to adhere to his medicines for the period and this negatively impacted his immunity. *"The deterioration in his health caused episodes of sickness and I left my job to permanently look after him"*

The research found that COVID-19 and its impact on social, economic and physical stability was repetitively mentioned as a challenge by most of the respondents. Due to COVID-19, many caregivers have lost their livelihoods and jobs, the teachers, snack sellers, car sellers, and all the

other people categorised as non-essential workers are not able to work, the casual laborers are not allowed to enter other people's homes and hence the caregivers have either been left unemployed or have resorted to some other work like laying bricks. A caregiver mentioned that they were not working since the lockdown, she had lost her job which greatly impacted the income of the home. Her adolescent had since become very stressed and concerned. She stopped eating food because they were only cooking beans and silver fish which to her were considered bad food. The adolescent would run away from home during that period and she would go get food from the men in the area in exchange for sex. *"I am always worried about her having to infect other people with HIV since she is not adhering to her medicines and each time i speak to her about it, she starts self-harming all over again".* Ms Kangave a counsellor added that, due to COVID-19, the transport system was halted and the adolescents were given medication for more than two months, monitoring the progress has become hard especially for the adolescents whose viral load is undetectable.

Furthermore, the research found that most adolescents who self-harm are extroverted and living in context of the lockdown complicate the situation further as they are not able to leave their houses or socialise with their peers. The result is a heavy load that is directed to towards the caregivers as they are given no option but to choose between attending to the ALHIV who self-harm or attending to their economic work. Nalugo, a caregiver, mentioned that her adolescent is highly extroverted and that the lockdown made it very challenging to support him. He is always throwing tantrums, shouts at his younger siblings including his mother. The mother is therefore not able to leave home because apart from self-harming, the adolescent is violent to both the community and the siblings. Many people in the area have taken advantage of her complexities at home to fetch water for free and brought losses to her tap managing role. Nalugo shared that she is getting warnings from her employer and she might lose her tap managing role if the lockdown continues.

> *"I worry that I might lose him to the mob who are equally frustrated, the lock down does not allow him to move, police is everywhere and curfew time is very strict besides, they are not allowed to gather in groups and so I must stay home and protect him"* ***(Nalugo, interview)***

The findings suggest that the caregivers can easily access ARVs and any HIV related medicines. The Uganda network of young people living with HIV and reach out-Mbuya easily connects them to the HIV clinics within their reach. One of the caregivers mentioned that when she escorts the Adolescent to reachout, they only wait for a few hours before they get attention. At reach out, all their medicines are catered for including medicines of opportunistic infections. In another contrast, Fahima, a caregiver mentioned that when she was referred to another health centre to receive the treatment related to mental health support of the adolescent, she was not able to access the full package of services. She was required to buy the medicines from the pharmacy. *"Buying the medicines means that I must spend transport to get to the health centre and also spend money buying the prescribed medicines which demotivates me from thetaking the*

Adolescent and hence wait for her to be very sick" **(Fahima,interview)**. The inability to access health services as required constraints the time and ability of the caregivers to attend to other equally important work.

The economic burden carried by the caregivers is one of the most challenging issues according to the respondents. Caregivers reported that apart from providing basic needs like food, and tuition, they have to live with another person in case they go away for work. The person's duty is to solely look after the ALHIV who self-harms. A brother who is a caregiver said that he must leave someone home when he goes to work because he doesn't trust that the adolescent will be safe on his own. Staying with an extra person requires more money to cater for two individuals hence creating an economic burden.

The research findings pointed out the cultural norms such as women are nurturers and hence must stay home, keep it clean and be the caregivers, men however are breadwinners that drive gender roles and norms. Many of the caregivers to the adolescents were women especially those that are married. Nankinga mentioned that it's her sole responsibility to bring family income as the husband doesn't have a job in addition to taking care of all the children and grandchildren. She further elaborated that her husband just stays in the house and doesn't do anything to support the home wellbeing including not taking care of the ALHIV who self-harms. In another account, Nalugo shared that since she is a single mother, she is always attacked by the community that the reason her child is self-harming is because she doesn't know his father. In her words

> ***"I am a laughing stalk in this community. No one sympathises with me even my fellow women. When my child commits a crime like theft or when he resumes self-harming, I am condemned and told that its my prostitution that is making me suffer". Nankinga, interview***

Dr Rujumba a key informant shared that culturally, self-harm is something rare so it will typically be attributed to the cultural beliefs which makes it hard for people who have it to seek medical services.

The research findings suggest that the caregivers are not professionally trained to do some roles that they do including counselling skills, nursing duties and a general understanding of the issues that affect their adolescents' health. Many of the participants mentioned that they do not know what to do when the adolescents relapse. In addition, the respondents reported that they are not sure on how to handle the triggering environments including their area of residence, remembering of their dead loved ones and lack of money. One participant, an aunt and a caregiver said *"ever since he lost his mother, he failed to recover. That is when he started self-harming and whenever situations become tough, he gets triggered".* Nankinga was also concerned about the men and boys that have sex with her step daughter. She mentioned that *"I get worried because even after counselling this girl, I understand that the environment she stays in influences her character. We stay in a ghetto where all sorts of bad behaviours are born. I asked her mother to take her to the village to stay with her but the mother said that she cannot handle how spoilt the child is and she cannot let her other children see herself cutting".*

The other challenge mentioned by the participants is the high levels of stigma and discrimination that they receive from the community. Nalugo, in her diary recorded she remembered a day her adolescent was sent away from school because he had missed classes for a long time. To protect the child, she asked her mother to escort him back to school and explain the situation to the teachers. The grandmother was unfortunately not subtle and she disclosed his HIV status and self-harm episodes. The other students bullied him since and he refused to go back to school. That is when the lock down happened. Nalugo is not certain that the adolescent will be able to go back to that school again when the schools reopen. The double stigma got from the society because she has an ALHIV who self-harms creates missed opportunities as people do not want to associate with her so they will not hire her for a job to earn a living. In many cases, society rebukes them so they have to have two personalities, one in public and the other in private. For instance, some caregivers mentioned that they dissociate with the adolescents in public, especially the ones who are not related to them.

The researcher found that caregivers are challenged by the negative behavioural practices that their children participate in like theft, COVID-19 and its impact on social, economic and physical stability was repetitively mentioned as a challenge by most of the respondents, most adolescents who self-harm are extroverted and living in context of the lockdown complicates the situation further as they are not able to leave their houses or socialise with their peers, the caregivers can easily access ARVs and any HIV related medicines but not mental health related support, the economic burden carried by the caregivers, the cultural norms such as women are nurturers and hence must stay home, keep it clean and be the caregivers, men however are breadwinners that drive gender roles and norms, most of the caregivers are not professionally trained to do some roles that they do including counselling skills, nursing duties and a general understanding of the issues that affect their adolescents' health, there are high levels of stigma and discrimination that they receive from the community.

ROLE CONFLICT:

The research found that there are role conflicts in regard to aspects of their roles and the role expectations in regard to looking after the ALHIV who self-harm.

It was reported that there is a high level of co-dependency of adolescents which conflicts with the time constraints on economic work availability and performance. The participants in the research were deeply concerned about the fact that the ALHIV who self-harm under their care are not independent enough to survive given the environments they live in. The lack of independence ranges from inability to remind themselves to take medicines on time, inability to cook for themselves and lack of motivation to do most of the work that other young people their age do. *"I break each time I look at her and she is not able to support her children and or herself. I warned her when she got pregnant at 14 that she is not ready to look after her child but she didn't listen, she gave birth and conceived again immediately after the first pregnancy. She gave birth again and I now have two extra people to look after"***(Nakinga, interview).** In situations like these, caregivers like Nankinga have to fore go economic work to be available for the ALHIV who self-harm most of the time and hence impact on the income of the family. From the notes taken from

the recording of the diary, Musimenta a caregiver, broke down in tears while accounting for how his day had been. He mentioned that he has been sitting at home since morning and yet there was an opportunity to help the builders at the site. He had been called but was not able to go due to challenges his girlfriend was facing that morning. She was pregnant and had refused to eat anything because all the sharp instruments had been hidden away from her. According to the recording, the day was a weekend and Musimenta couldn't get to the health centre and he couldn't leave her to go to work. It impacted him because this is the first opportunity he had to work after very many months of not getting a call although construction workers were considered as essential workers. The conflict like this was reported by all the respondents in their different role capacities.

In addition, the role conflict has unforeseen challenges like triggered episodes for the ALHIV who self-harm. In the account of Rebecca the student who supports her sister, she mentioned that there are so many days that she has had to leave school to make sure that she secures her sister's security. Through the diary, she mentioned that she had to leave her online exam because her sister had prepared rat poison in a cup to drink. She had not communicated with her school in time and she got a retake in class. In her quote *"this was not the first time something like this happens, I get frustrated and lack direction as i am younger than she is and I don't know how to handle the situations"*. Rebecca however mentioned that since lockdown, the conflict of having to choose school or looking after her sister reduced a bit as online school is more flexible and the only worry is whether she has the ability to concentrate fully in class.

Figure 5: one of the adolescents under care

The research found that many caregivers especially the parents regret and self-blame for having children who are not independent. This conflict according to the research was presented through choosing self-love among the caregivers and having to choose the ALHIV who self-harms. The caregivers reported that often, there is a tough choice of choosing themselves over choosing the adolescents they look after. Manjeli, a caregiver mentioned that she has often found herself under a lot of stress and depression because she doesn't pay attention to herself. When she is not able to get money for food especially during COVID-19, she has had to skip meals to ensure that the adolescent gets something to eat considering that he needs more medicines than she does. Manjeli is living with HIV and that alone affects her wellbeing. *"Sometimes I blame myself for not raising my child right. I see other adolescents thriving and happy which makes me feel terrible as a failed parent.* ***(manjeli, diary).*** Mr Bukenya Denis, a key respondent added that the choice between self (caregiver) and adolescent doesn't only affect the parents but it greatly impacts on

the lives of the other children in the household. In his experience, many of the adolescents who were co-dependent that sought his care were a liability to the whole family indirectly. Their needs must come before the needs of everyone in the household including competing with children below 5 years. This often kept conflict between the parents on whether they should be parents to other children or parents to one adolescent.

Further still, the research found that role conflict arises when a caregiver wants to guide the ALHIV who self-harms and at the same time fears to trigger their self-harm thoughts. The caregivers mentioned that it's easier to let the adolescent have their way than having to deal with the self-harm episodes. Nankinga elaborated that if her step child wants to go sleep over at a man's place, Nankinga becomes powerless and just lets her go because fighting with her causes trauma to the whole household.

ROLE STRAIN

According to the findings, the different roles come with different strains that the caregivers have to stretch to fulfil. Below is an account of the different role strains that the participants identified:

The research found that the ALHIV who self-harm have moments when they lack self-control. This especially happens to the ones who use drugs. Whenever they run out of drugs, they become fussy, and caregivers are scared of them at the moment. The caregivers are not able to speak to the adolescent as they are scared of what the reaction of the Adolescent will be. Mostly, the caregivers reported that it is always dangerous and it may cause harm to other people in the household including the caregivers themselves. Caregivers are kept unable to restrict behaviour due to fear and hence they strain their role of giving guidance.

> ***"I get scared of him sometimes because whenever he asks about his father's family and I don't give him the response he is expecting, he becomes rowdy and threatens to beat me. This always leaves me heartbroken as I would want to support him but I am not able to help him. I cannot give him advice although I know that is my responsibility and this keeps the situation complicated". Nalugo, interview***

More so, some caregivers have gone as far as buying the drugs especially when the ALHIV starts shivering. Because they do not have access to professional care, the caregivers buy the drugs that the adolescents use to enable them to calm down. According to Dr. Kinyanda, the irony of the situation is that the role of the caregivers is to support the ALHIV to stop the use of the drugs although they buy for them the drugs. Many of the caregivers lack knowledge on the medical substitutes and hence continue to provide the ALHIV with drugs.

The research also found out that the caregivers strain their role of protection of their adolescents versus protection of the community. Many of the ALHIV who self-harm are forced to steal from other people including their family members. However, most of the time when the caregivers learn about this, they do not report their adolescents to the community. This act promotes the theft behaviour as the adolescents learn that their caregivers will protect them over protecting

the community. Kwagala, a brother and a caregiver to one of the ALHIV who self-harm, said that his brother gets tempted to steal all the time and whenever he learns about the theft, he doesn't report because of the already existing stigma around his mental health and his HIV status. *"I know it is wrong for him to steal but I also do not want him to be beaten or taken to prison so i will hide him whenever he steals"***(Kwagala, interview)**

The findings suggest that there is a role strain on intimate relationships of the caregivers brought about by the role in protecting the ALHIV who self-harm. During data collection, the adolescents who live with their families that have both parents, there was reported strain on the relationship between the mother and the father, or uncle and aunt. The families divide labour in a way that one partner is more responsible for the wellbeing of the Adolescent and the partner is usually the female. Because of the hard work and daily routine, they usually fail to balance the care for the significant other. Evidently, Nankinga, a caregiver, reported in her diary a day when she was very exhausted but the husband demanded conjugal rights. She was not ready because her daily routine is exhausting as she has three children of her own to look after including her stepchild who self-harms and her two children. When Nankinga refused, her husband became verbally abusive. In another dynamic, the caregiver who is a nurse mentioned that the level of attention given to the ALHIV who self-harms has constrained the relationship between him and his girlfriend. The girlfriend complains that he takes a lot of time caring for the adolescent at the cost of the girlfriend.

> ***" I stay at hospital quarters with a single room. The space is small and also we have a limit on the number of people we can let sleepover. My girlfriend doesn't feel at ease with the arrangement, especially because we cannot be free with each other when the adolescent is around. She is also concerned about what would happen if we decide to start a family"*** **Caregiver- interview**

Furthermore, the role strain presented around the provision of needs for the rest of the family versus provision of needs for the ALHIV who self-harms. One of the caregivers mentioned that it takes a lot of money to look after one ALHIV who self-harms and this may come at the cost of everyone else. The caregiver is just a concerned person not related to the Adolescent but he compared the money he spends on the adolescent as more than that he spends on his family of four in a day. In his words *"I spend 20,000 Uganda shillings a day (an equivalent of 5.5 USD) on a single person. It includes expenditures on airtime to check on him every few minutes or maximum of one hour, his food and the money I give him for transport to commute to his work"*. This situation strains the amount he gets to spend on his family as he doesn't earn as much money.

ENABLING FACTORS THAT SUPPORT THE CAREGIVERS:

According to the findings of the research, much of the contribution was given to the role of non-governmental organisations like reach out, Baylor Uganda harm reduction and UNYPA. The participants mentioned that those and other organisations are responsible for supporting their HIV related care. In addition to the programme that UNYPA has to support their education around mental health, living positively and selfcare. One caregiver mentioned *"The adolescents are*

invited for meetings and peer supporting sessions. The process is gradual but there is progress especially for some of the Adolescents who have prioritised change. Sometimes they come back with money and other times with food supplements to support them in taking their medicines on time. Besides when they interact with their agemates who are successful like the young people who work in those organisations, they draw motivation to live healthier and stay on the medicines that support their wellbeing" **(Friend, diary)**

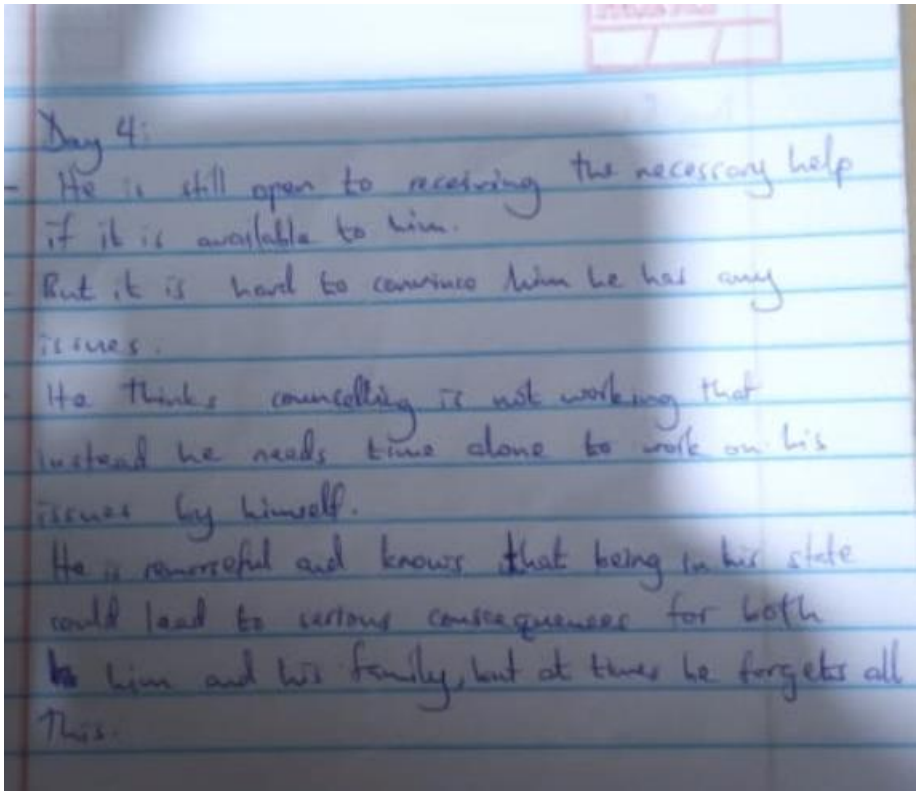


Figure 6: Sample of diary written by the caregiver

The research found that churches are also supportive factors where they go and seek refuge from the judgement. One caregiver is a songwriter in church and he asks the adolescent to join him in prayer every day. He mentioned that they have morning glory prayers and evening prayers with the adolescent to help give him a reason to fight.

Furthermore, the availability of income and work to support the needs was also an enabling factor that was mentioned. However, the onset of COVID-19 changed this dynamic. The caregivers mentioned that before covid-19, things were easier than they are now.

The support of having another person in the house to take care of the adolescent was mentioned by the caregivers. The caregivers who live with another adult in the house reported that caring for the adolescent is not as challenging as they can leave the adolescent and go to work or find work. One of the participants mentioned *"since the visit of her other aunt, I have not been finding many difficulties as I used to. Her aunt and I leave home in intervals and that supports me to look after him effectively with some money in my pocket"*

The factors that enable caregivers to support the adolescents include: access to HIV related services, access to peer educators and role models, the role of church in providing comfort to that caregivers and their adolescents, the availability of money and incomes to those who were still able to work under the lockdown and the availability of support of other family members.

SUPPORT NEEDED BY THE CAREGIVERS:

The participants in the study mentioned the need for skills building to enable them start employment for themselves, especially employment that earns them enough money to support the adolescents. One caregiver mentioned that skills like hair braiding would have come handy during this period where COVID-19 hit and people were not able to work. In addition, they mentioned that the need for this is because the ALHIV who self-harm are very expensive and hence looking after them requires one to have more money than they have.

> "*If there is a way, I could get capital to start up something like selling tomatoes. I know if I am selling them, I can easily get some money which can help support the home in a day. Because I need to be near the adolescent and not leaving him for long hours because the adolescent depends on me, I also have to cook for him"* ***(Mother, diary)***

To support further, there is a need for community sensitisation to reduce the high stigma and demoralisation that the caregivers and the adolescents face due to their health status. Participants mentioned that they struggle a lot with the community and meeting the needs of the adolescents since they are not able to express freely in society and they live in fear of the unknown judgement and criticism forwarded towards them. One of the participants quoted *"When my girlfriend self-harmed and tried to commit suicide, society condemned her so much that she has now withdrawn from interacting with the community. She is discreet about her movements to ensure her safety"*. Dr. Kinyanda elaborated that the stigma is rooted deeply into the society and that it might be acceptable as a practice. However, people promote stigma due to lack of proper knowledge around the causes, modes of transmission where applicable and factors that include lack of access to health centres to treat the Adolescents better. He quoted *"we can do better, it is already challenging enough not to have access to routine support and treatment but having the community aware of these issues will support the ALHIV who self-harm heal better"*

The participants also mentioned the need to receive training on basics of caregiving and support like counselling, nursing wounds and to create self-awareness sessions for caregivers. One participant shared that the degree of calmness and the level of self-preservation and patience required to take care of the ALHIV is not naturally produced by everyone. Caregivers need support to be self-aware so that they build patience and resilience of the rage that comes from the adolescents in many cases. Ms. Ayabare the clinical psychologist added that the caregivers require a lesson like the one they take as clinical psychologists but in a simplified and less

complicated language. She suggested that it should be a session carried out like that of antenatal care as the caregivers wait in lines to receive health services. This saves the clinical caregivers and the home based caregivers a lot of the challenges faced during care.

The participants shared that the ALHIV needs recreational spaces in their communities to support the diversion of their energy into more productive physical work. Musimenta, a caregiver shared that her sister is very interested in netball and having a netball playground can support her to spend time on something other than thinking, being lonely or stressed. This means that Musimenta will have enough time to attend to other tasks that are equally important and are in the same line. In an interview with Dr Rujumba, he confirmed that although play and sport could be a good use of the energy, it is not guarantee that the adolescent will stop self-harm. It allows time and space but should not reduce the monitoring of the activities, group dynamics and social interactions of the adolescent.

More to add, the research found that caregivers need materialistic support like food supplements, sanitary wear for girls as it is expensive and maybe scholastic materials to help the students stay in school longer. One participant mentioned that whenever the adolescent starts self-harming, she forgets about her use of pads when she is in an episode but when the pads are around in the house, she easily wears them. The food supplements are also important because the adolescents are not able to eat a balanced diet everyday which scares their health and their well-being all together.

> ***"our wellbeing (caregivers) depends on the wellbeing of the adolescents that we support". Mother, diary.***

The participants mentioned that some of the support needs they require include: need for skills building to enable them start employment for themselves, especially employment that earns them enough money to support the adolescents, the need for community sensitisation to reduce the high stigma and demoralisation that the caregivers and the adolescents face due to their health status, the need to receive training on basics of caregiving and support like counselling, nursing wounds and to create self-awareness sessions for caregivers, the participants shared that the ALHIV need recreational spaces in their communities to support the diversion of their energy into more productive physical work.

Chapter 4. DISCUSSION:

The anticipated impact of COVID-19 on the quality of responses received in this study was underestimated by the researcher. By the time of data collection, the country was under a strict lockdown and particularly Kampala where the division of focus is located. Most of the responses were influenced by the situation as caregivers had lost their jobs, were not able to travel and the curfew impacted on the quality of work that the caregivers do. According to the research, there was a uniformed response that directed the heavy shift of impact and relations in terms of roles, enabling factors, challenges and needs of the caregivers. COVID-19 has compromised the quality of care to the ALHIV who self-harm.

According to a study by (Niedzwiedz 2021) in the UK, the first month of lockdown increased distress with the prevalence rising from 19.4% in 2017-2019 to 30.6% in April 2020 affecting mostly women and young adults. It is by no surprise that the caregivers are mostly women and they were highly impacted in Nakawa division as well the ALHIV who self-harm. The participants mentioned that the adolescents they look after are mostly introverted and the lock down instigates ill mental health as they survive and nourish better through interactions. It should however be noted that the lockdown was a blessing in disguise for some of the caregivers as they got ample time to take care of the adolescents without worry and scare and spending more money to hire a caregiver to stay at home while they go to work.

Too often, the caregivers of ALHIV who self-harm carry as much burden or more as the adolescents themselves. The issues, challenges and problems that impact the lives of the adolescents they take care of parallelly affect the caregivers although the medical and social interventions usually neglect the inclusion of the needs of the caregivers. The discussion below is structured along the four sub questions in these thematic areas including: the different roles of the caregivers, what enables caregivers to support adolescents, challenges faced by the caregivers in supporting the adolescents, the support needs of caregivers of ALHIV who self-harm that rose as the analysis of the results happened:

DIFFERENT ROLES OF THE CAREGIVERS:

The caregivers of ALHIV who self-harm are key facilitators for the help-seeking, help sustaining process for the adolescents. According to Curtis (2018) the impact of self-harm is substantial and there exists a discrepancy between the most common parental responses and the preferences of young people. In addition, parents are often reluctant to seek help for themselves for various reasons including time limitations, feelings of being incompetent, guilt and shame. Most of the caregivers who participated in this research reported that they have to disguise their image in public to suit the expectations because of the societal expectations that are used as a yardstick for parenting. Specifically, all adolescents are expected to thrive, grow and discover who they are without causing harm to themselves, much worse living with HIV at a tender age. Most caregivers, especially the parents of ALHIV who self-harm, live in guilt, shame and that alone hinders them from fully participating in the seeking of help to better improve their roles.

Figure 7: Adolescent going to help her caregiver

It was surprising to find that most of the caregivers are aged relatively close to the ALHIV who they support (below 27). The researcher was intrigued to understand why there are so many young caregivers. She questioned and found out that many of the ALHIV who self-harm under the care of their friends are from wealthy families and they do not feel comfortable staying in their homes because their parents do not comprehend their needs and therefore cannot fulfil their roles effectively. The ALHIV then move to areas where they feel more comfortable and end up with friends and at the mercy of strangers who later become friends. The adolescents still seek support from the organisation. The relatedness of the caregivers and closeness to age with the Adolescents under their care has an impact on how the role as a caregiver is handled. The caregivers still have to attend school, they have young families and they have to navigate their own lives which restrains their role and conflicts as mentioned in the findings. Carter (2010) affirms that for younger caregivers, the negative variables include 3 dimensions of strain; strain from lack of personal resources, strain from worry, and global strain.

ENABLING FACTORS FOR CAREGIVERS:

The findings discussed in the previous chapter identify the enabling factors mentioned by the participants. They mentioned the role of non-governmental organizations as a source of support. However, the degree and level of support awarded is at the minimal and may not be as affirmative. Sebunya et. al (2018) argues that In spite of the pronounced adverse economic consequences of mental and substance use disorders on households in Uganda,, service coverage and financial protection for these families is very limited. one could also argue about the sustainability of the support and the role of government in supporting communities of ALHIV who self-harm. Notably, the government doesn't have a dedicated programme to support economic and social needs of caregivers of ALHIV who self-harm. There is a wide gap in the data and information required to deliver such an intervention. Ownership and sustainability of interventions by the NGOs is better placed when the government has supported direction and partnered to achieve this goal.

CHALLENGES FACED BY THE CAREGIVERS:

The study found that the challenges affecting the caregivers include: the negative behavioural practices that their children participate in like theft, COVID-19 and its impact on social, economic and physical stability were repetitively mentioned as a challenge by most of the respondents,

most adolescents who self-harm are extroverted and living in context of the lockdown complicates the situation further as they are not able to leave their houses or socialise with their peers, the caregivers can easily access ARVs and any HIV related medicines but not mental health related support, the economic burden carried by the caregivers, the cultural norms such as women are nurturers and hence must stay home, keep it clean and be the caregivers, men however are breadwinners that drive gender roles and norms, most of the caregivers are not professionally trained to do some roles that they do including counselling skills, nursing duties and a general understanding of the issues that affect their adolescents' health, there are high levels of stigma and discrimination that they receive from the community.

. According to a study done by Sheth et.al in 2021, stress, depression, caregivers' well-being, finances, and routine social activities have changed during COVID-19. The already stressed caregivers are trying to navigate these difficult times along with caring for friends or family. Most of the responses from the participants mentioned COVID-19 as an instigating force to the already existing disadvantages faced by the caregivers. However, one would question the positive attribute that COVID-19 has impacted on the community. Before covid-19, the relation to depression was a foreign idea(perceived but not acknowledged) to most of the Ugandans, but during the lockdown, many of the attitudes of people changed towards the causes and course of mental health (O'Connor, C,2021) the shift impacts on the role strain of the caregivers as presented by William J. Goode's (1960) role strain theory.

Indirectly, there will be an anticipated shift in the stigma and discrimination of the ALHIV who self-harm and their caregivers. According to Shah et. al, 2017, the stigma surrounding mental health and its treatment is one of the greatest barriers to mental healthcare. Despite the high prevalence of mental illness in Uganda, previous studies have consistently demonstrated the presence of stigma among the general population where HIV patients, survivors of abuse, and rape survivors are at increased risk but often fail to seek treatment because of stigma and fear of retribution. In my view, stigma towards the caregivers strains their role within the society thereby limiting the quality of care they offer to themselves and or the adolescents they care for.

The gender aspect cannot be ignored according to the results. Women carry the burden of multi-tasking in different roles that cause role conflicts in homes and society as they look after the adolescents. In the same instance, most of the role strain that women face is because the male partners are not contributing equally to support the household in general. However, in a survey done by Kipp, et.al (2006), in understanding the care burden for persons living with HIV, both male and female caregivers reported a similar burden. In my view HIV is a more behavioural disease so the results may differ from those of mental health related care. This does not refute the fact that in Uganda, when children are intelligent and 'normal' they belong to the father but children who are less advantaged in intelligence or have an 'abnormality' are attributed to the mother hence a high possibility of the father neglecting responsibility when it comes to an ALHIV who self-harms.

SUPPORT NEEDS OF THE CAREGIVERS

The support needs of caregivers were presented as, education for self-awareness, creation of recreational spaces for the adolescents in their community, provision of skills for empowerment, training to enable caregiving skills like proper counselling or wound management techniques. According to the findings, caregivers require support to navigate the implementation of the different roles and understand the level and quality of support that their adolescents need. The enlightenment ensures that the caregivers understand the basics like counselling and guidance procedure, proper wound management, self-awareness that supports calmness while handling a difficult case. Caregivers themselves require counselling to support stabilisation of their own mental health to ensure that it doesn't get impacted by the strain and conflicts of the role they serve. In a study done by Curtis (2018), caregivers are often reluctant to seek help (formal or informal) as a result of the immense feelings of shame and guilt that they experience in relation to their child's self-harm. This is particularly problematic as adolescents prefer that their parents or caregivers facilitate connections with informal support such as teachers

The researcher found that care givers need support to intervene in drug use of the adolescents as most of the adolescents who self-harm also use excessive drugs which leads to poor mental health outcomes. The poor mental health outcomes drive them into inflicting harm on their bodies by trying to use the ARVs that they receive from the health centres to overdose. When they do not have access to the ARVs they use rat poison. The excessive use of drugs contributes to the fussy and unruly behaviour and forces them into crime like theft.

REFLECTIVITY:

In order to be not mere technicians but competent practitioners of research, a researcher should be able to reflect on their work in a deep way. That means they should reflect not only on the practical acts of research but also on the mental experience which constructs the meaning of practice. Reflection is a very important mental activity, both in private and professional life. Mortari (2015) As a professional with experience of working with Adolescents and young people living with HIV, below is my reflection regarding the research.

The experience of carrying out research from the Netherlands was quite an opportunity to learn and unlearn traditional channels of researching. It is different carrying out data collection in person and carrying out data collection online. With the key informants especially and their busy schedules, I had to reschedule the meeting several times before I could get to have a meeting with any of them. It was very challenging.

With the experience of my previous data collection, the rapport built with communities is different in person than that online. I was so glad to have flexible participants who did not find internet a threat although they kept reminding me that I may not take their photos with screenshots.

As a researcher, I enjoyed working with the community as they gave me an opportunity to reflect and learn more about myself. Every time we carried out the interviews, they were willing to share

openly with me and that gave me resilience to persevere through the situations where I could have broken down. Particularly for Nankinga's step daughter, I kept trying to hold my tears back as I analysed her situation of being a teenage mother of two babies that she is not able to support.

The journey to collecting data gave me courage to approach top researchers in the country to provide information on the aspect. The balance was challenging but bravery was something I took away from the research.

Chapter 5. CONCLUSION:

The caregivers of adolescents living with HIV who self-harm have different roles such as being a parent, being a sibling, being a partner (girlfriend or boyfriend) , nurse, counsellor, worker, Student. The different roles come with different responsibilities including: Supporting the family financially, being present to look after the Adolescent who self-Harms, have fun with the ALHIV who self-harms ensuring that they are happy, being supportive while giving love and care gently, giving emotional support, providing guidance when needed, providing medical help like cleaning wounds, be present at work every day and on time, be at school, do well in class.

These roles however present challenges including: limited access to desired health services, COVID-19 and its economic, social impact, negative behavioural practices, lack of training on how to handle ALHIV who self-harm, non-progressive cultural norms, stigma and discrimination, lack of access to basic needs. Due to these challenges, caregivers find themselves at crossroads with roles conflicting with each other. For example, co-dependency of adolescents conflicts with the time constraints on economic work availability and performance for the caregivers, conflicts of having to choose self-love for the caregivers without hurting the ALHIV who self-harms, conflict also arises when a caregiver wants to guide the ALHIV who self-harms and at the same time fears to trigger their self-harm thoughts.

The roles also present different strains as mentioned by William J. Goode's role strain theory. Role strain in the research presented when a partner in an intimate relationship loses is not able to give time to their intimate relationships because they are protecting the ALHIV who self-harms, the question on provision of needs for the rest of the family and provision of needs for the ALHIV who self-harms also causes role strain for care givers, more so, the caregivers strain their role of protection of their adolescents versus protection of the community. Many of the ALHIV who self-harm are forced to steal from other people including their family members whenever they do not have access to drugs. However, most of the time when the caregivers learn about this, they do not report their adolescents to the community thereby straining their role.

To sum up the conclusion, the results from the research have further proven William J. Goode's role strain theory. Due to the many challenges and the different responsibilities that the caregivers have to play, their ability to effectively and efficiently accomplish all of the tasks diminishes. This is because of the effects that impact ALHIV who self-harm are synonymous to the role conflict, strain and burden of the caregiver.

Chapter 6. RECOMMENDATIONS:

As a starting point to support the caregivers of ALHIV who self-harm, my recommendation are mostly suggested to Y+ Global:

To support the caregivers to fulfil their different roles, I suggest that Y+ Global looks at the possibility of providing routine counselling services to the caregivers. The services might be made door to door as home visits partner with a counselling agency specialised in providing services to caregivers of adolescents or recruit a full time staff to be located at one of the friendly centres to specifically support the caregivers. Many of the caregivers are not sure of what to do and hence routine counselling may provide comfort and mental relaxation to do their roles appropriately. This will also support the caregivers who are parents to reduce the shame and guilt they carry because of how their adolescents live.

In addition, I recommend that community sensitization is done routinely to create awareness of the challenges of mental health which will reduce the stigma and discrimination geared towards the caregivers and the adolescents themselves. Community sensitisation can be done at community halls, playgrounds or locations where gatherings can be allowed.

More so, I would recommend that Y+ Global organise skills training sessions. This is to support the income generation sources of the caregivers. Since the research was carried out during the COVID-19 pandemic, the caregivers appreciated alternatives to their usual income sources that were not operative during the lockdown. The skills such as hairdressing will support flexibility in working from home as well as look after the adolescents with convenience.

Finally, I recommend that another study be carried out to understand the type of care that ALHIV would like to receive from their caregivers. It is important that the care needs of adolescents are addressed especially since Y+ Global stands for the ethical engagement of young people.

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ANNEX:

ANNEX 1: CONSENT FORM

Title of Research: Support needs for care givers of adolescents living with HIV who self-harm in Nakawa division, Kampala district, Uganda

Lead researcher, Affiliation and Contact Information:

Kyendikuwa Allen N, Global Network of Young People Living with HIV, kyendikuwa@gmail.com

Research assistant and Affiliations: Nalugo Sharifah, international community of women living with HIV East Africa. Leticia Akumu, UNYPA

Introduction and Purpose of the Study

The study aims to understand the role strain and role conflict of caregivers of ALHIV Who self-harm. We want to learn the challenges faced by caregivers and how the challenges make it hard for them to look after the young people as they work on other things too.

Description of the Research

When the research begins, you will be asked a few questions and because the questions are not written down, we will follow up each question depending on the answer you give.

In addition to this, answers will be got from your diary that you have been writing for a month.

The study will also use phones to record your daily routine

We will follow up in case more questions arise as we analyse the data.

Subject Participation

We estimate that 20 participants who are caregivers of YPLHIV who self-harm will enroll in this study. Participants must have been caregivers for at least 4 months and be located in Kampala district, they should be able to communicate verbally and able to use a smart phone Your participation will involve three visits, approximately 50 minutes in length for the first visit.

Potential Risks and Discomforts

The information in this interview is very private and personal and might request sharing of very private information which will be discomforting including education level, age and economic status.

Potential Benefits

Your participation in this study will provide information on the needs of caregivers of young people who self-harm. This information will give evidence to building a project that will support an introduction on a new project.

Results from this research will be shared with you

Confidentiality

The information in this study will be recorded on a recorder to help the lead researcher analyse the data. Once audio recordings are coded and transcribed they will be destroyed However, all information taken from the study will be coded to protect each subject's name and will be confidential only accessible to the research assistant and the lead researcher in this study. No names, locations or other identifying information will be used when discussing or reporting data. The research assistant will safely keep all the hard files and data collected. Once the data has been fully analyzed it will be destroyed.

Authorization

By signing this form, you authorize the use and disclosure of the following information for this research.

I authorize the use of my written diary, any observations seen during the interview, and findings found during the course of this study for education, publication and/or presentation.

Voluntary Participation and Authorization

Your decision to participate in this study is complete voluntary. If you decide to not participate in this study, it will not affect the relationship you have with the organisation.

Withdrawal from the Study and/or Withdrawal of Authorization

If you decide to participate in this study, you may withdraw from your participation at any time without penalty. However, if you choose to withdraw, the information shared before the withdraw may be included in the study.

Reimbursements:

> We will provide all the material needed to make diaries to each participant and there is no cost for participating in this study. However, every participant will be given a minimal transport reimbursement of 10,000 UGX to cater for their transport based on local costs.

I voluntarily agree to participate in this research program

☐ **Yes**

☐ **No**

I understand that I will be given a copy of this signed Consent Form.

Name of Participant (print):_____	
Signature:	Date:
Name of Witness (print):_____	
Signature:	Date:
Person Obtaining Consent:_____	
Signature:	Date:

ANNEX 2: SEMI STRUCTURED QUESTIONAIRE FOR CAREGIVERS

1. What is your age?
2. What is your relationship with the young person
3. When did the young person start to self-harm?
4. How long have you been looking after the young person who self-harms?
5. Share with us your daily routine(what you do on a daily basis to look after the young person)
6. What supports you to be able to support the young person who self-harms?
7. How often does the young person need support
8. Do you work? If yes where do you work or what do you do?
9. How do you balance the time between looking after the young person and your work?
10. Do you think that supporting the young person impacts on your job? Why or why not?
11. What are the challenges you face and why do you think you face them?

ANNEX 4: SEMI STRUCTURED QUESTIONAIRE FOR KEY INFORMANTS:

1. What are some of the services available to support caregivers of ALHIV who self-harm?
2. What are some of the challenges faced by caregivers of ALHIV who self-harm in accessing the services they need?
3. How do the challenges contribute to their role strain?
4. What brings about role conflict in supporting the ALHIV who self-harm?
5. What role has COVID-19 played in further complicating the situation

ANNEX 5: SAMPLE INDICATORS FOR BASELINE VALUES: BENCHMARK FOR PROJECT PROGRESS.

	BASELINE VALUES			
Indicators	Overall	By age	By sex	Comments
Number of caregivers in Nakawa Division				
Number of caregivers with the correct information about caring for ALHIV who self-harm				
Number of caregivers who have paid work				
Amount of time spent by care givers with the ALHIV who self-harm				
Number of people under the care of the caregiver				
Degree to which ALHIV who self-harm are allowing to access support				