



**THE PSYCHOSOCIAL NEEDS OF ADOLESCENT YOUNG CARERS AND THE  
WHOLE FAMILY APPROACH MODEL RELEVANCE IN THE TIMES OF COVID19  
PANDEMIC.**

**PERSPECTIVES OF SOCIAL WORKERS FROM LIRA (UGANDA)**

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## ABBREVIATIONS

CPC	Child Protection Committees
PSWO	Probation and Social Welfare Officer
CDO	Community Development Officer
AYC	Adolescent Young Carer
YC	Young carer
PSS	Psychosocial Support Services
WFAM	Whole Family Approach Model
VHT	Village Health Teams
UNCRC	United Nations Convention on the Rights of the Child
LRA	Lord's Resistance Army
FGD	Focus Group Discussion
LC	Local Council
NGO	Non-Governmental Organisation

### Abstract

The outbreak of Covid19 pandemic led to a lockdown in most countries globally confining adolescent young people at home with limited access to essential services critical for their development like education, health, youth services, and recreation. For the adolescent young carers, such measures like physical distancing from family, friends and community only increased their isolation without clear information of where to get support services. This study investigated the feasibility of the Whole Family Approach Model relevance in responding to the psychosocial needs of the adolescent young carers in Lira, Uganda. The study employed a qualitative method of research and adopted a case study design. A total of 3 case studies detailing the lived experiences of adolescent young carers were documented and shared with the researcher, and based on this, semi-structured interview guide was developed and administered to 9 social workers from TPO Uganda and those who worked in the probation and welfare office and sub county level community development offices in Lira district. The study findings from the research highlighted some of the psychosocial needs of adolescent cares as the need for parental love, care and guidance, the need for belonging, for personal freedom to engage in activities that made them happy, built the friendship and offered peer support. In regard to the relevance of the WFAM, findings show that there were significant barriers that hampered the utilization of the approach and therefore it was not fully relevant during covid19 pandemic. It is recommended that social workers should be prepared to contextualize the model approaches that they use, based on the situation at hand rather than a stiff pattern .

**Key words:** Young carers, Adolescents, whole Family Approach Model, psychosocial needs, COVID-19

## CHAPTER ONE

## 1.0 Introduction

Based on practice experience, adolescent young carers constitutes a category of children and young people who performed informal care roles that are almost normalised by society. Considering the care roles they perform, they deserve to be protected from exploitation and abuse that may occur during the course of their work. It is interesting to comprehend the kind of internal strength that some of them develop to cope with their roles and yet only a little support seem to come from their external environment. According to existing literature, adolescent young carers are in every country (Becker, 2007; Nap et al 2020 ) and therefore should be of interest to social workers to find out more about them and support them as they transition into adulthood. It is also the role of social workers who has a key mandate in promoting social justice to advocate for the rights of such a category of adolescents whose roles are almost invisible. Based on their hidden nature they seem to be a minority group who are most often left behind in services.

This chapter provides the background to the study, problem statement, research aims and objectives, the main research questions and the significance of the study.

## 1.1 Background of the study

Compared to other children and young people, adolescent young carers are limited from fully enjoying their rights because they are pushed to the edge by circumstances affecting their loved ones who may be chronically ill, have a disability, mental illness or take care of their siblings due to death of parents or caregivers (Becker, 2002; Aldridge, 2018). They perform a range of tasks in the home that are not commonly done by young people of their age group but are like adults responsible for domestic chores, “*sometimes intimate, specialised and medical care*” (Aldridge, 2018). As highlighted by Aldridge, medical care would entail going with them to the hospital, helping them to take their medication as prescribed by the doctors, providing basic counselling to them. Evidence from previous research also shows that caring is mostly a gendered activity (Aldridge 2018) that may disproportionately affect boys and girls. Since 1993, there has been growth in research about the young carers that has led to increased awareness of who they are and what roles they play in informal care

especially in Europe (Becker, 2019; Joseph et al, 2019). This research endeavoured to establish the situation of adolescent young carers in the context of COVID19 which is the most recent pandemic affecting the world.

In March 2020, the world almost came to a halt when the World Health Organisation declared Covid19 also known as Corona Virus a pandemic (WHO, 2020). Started in Wuhan China in December 2019, and spreading quickly to Europe, United States of America, Asia, Africa, Oceania, covid19 has become one of the greatest public health emergency of our time . By the 05 June 2021, over 172 million cases were confirmed and 1.6 million deaths registered globally (WHO, 2021). Psychologically, it is projected that the young adolescents may resort to negative coping strategies because of the limited access to support services that acted as a safety net for them before the lockdown (Save the Children, 2021). One of the most immediate effects on the young adolescents, especially girls in sub Saharan Africa based on the guidance notes from humanitarian actors is the increased burden of care for the sick family members and care for siblings in the aftermath of parental death (Compact for Young People in Humanitarian Action, 2020). Similarly there is a gap in research about the impact of caring on gender roles (Becker, 2020; Aldridge, 2018) that corresponds with the comments from reports by national and international non-governmental organisations such as Save the Children. Previous literature on young carers conducted shows that even though some Young carers find caring as an opportunity to prepare themselves for adult life (Joseph et al, 2019), AYC in general struggle to cope with caring responsibilities (Becker, 2019; Nap et al, 2020;) and that requires interventions to enable them deal with the changes happening to them. Such psychosocial support interventions can be offered at different levels where level one is the caregiver and family support psychosocial care and support, level two refers to the community and services support and level three is the focused-non specialised support.

In Uganda, prior to covid19 pandemic, adolescent young carers lacked institutional support (Save the Children, 2010). Caring is mostly normalised and considered reciprocal (Daly and Lewis, 2000; Robson 2003) and the care burden is normally on

the extended family with women and girls taking most of the roles due to the social construction of caring (Hunt and Powell, 2013). When it comes to support services for the adolescent young carers, there is no policy explicit about their needs and support services but they mostly receive support through the mainstream orphans and vulnerable children programme (Government of Uganda, 2020). The way psychosocial support services are provided to the adolescent young carers is related to the limited resources that has to be shared across the different sectors and the country tends focus its attention to address the infrastructural needs and health needs of the country. It has been argued by the previous researchers that supporting them through the mainstream child protection services seem to be a more reliable approach and considered to be more sustainable (NAP et al, 2020).

However, with the increasing number of covid19 infections seem to push the adolescent young carers even much further away from support services. Based on the experiences from the first nationwide lockdown, there was a realisation that a huge gap in psychosocial support was created which left many marginalised groups more isolated (Onyango and Veale, 2020) thereby affecting their mental wellbeing. In addition to that, the already weak health care systems got overwhelmed leading to government prioritising only covid19 related concerns to receive emergency support services. The government has declared the second nationwide lockdown (Government of Uganda, 2021) and even though there is more flexibility for the social service workers to reach out to communities, they are still constrained especially due to fear of contracting and transmitting the virus. Continued inability to access such essential support services could lead to psychological breakdown of the adolescent young carers and members of their families. In addition, compared to the first wave there has been a sharp increase in the number of people infected and death related cases in the country.

Inaccessibility to information can be one of the main barriers to adolescent young carers as the tools for communication are becoming more of media oriented and some of them do not have such tools while others have but it is limited by coverage and data. Bearing the burden to care for a sick relatives suffering from covid19 with lack of reliable information on safety, exposes adolescent young carers to infection if relevant support is not provided to them (Cluver et al. 2013; Leu and Becker 2017;

Blake-Holmes, 2020). Already there is increased fear and anxiety among carers as they do not want to get infected so that the disease affects the person in their care. Continued living in fear and inability to express it out could have long term psychological effect in their transition into adulthood (Blake-Holmes, 2020). Aldridge and other scholars suggests that interventions should focus on preventative measures targeting YC and the members of the family as a whole (Aldridge 2018; Becker, 2007; Nap et al, 2020).

This study therefore focused on investigating the psychosocial needs of adolescent young carers and the whole family approach relevance during covid19 pandemic in Lira district located in the northern part of Uganda.

## 1.2 Problem statement

Adolescence is one of the crucial stages of development in a child's life that comes with significant transformation in the body, mind and environment of a young person. Both girls and boys experience these changes differently that requires gender sensitive understanding. This is the stage Erik Erikson, the German psychologist referred to as identity vs role confusion in his psychosocial development theory (Lumen, 2021). During this stage, an adolescent is trying to form their identity by examining their personal values, beliefs and goals in life and they want to belong to the society. As a result, they focus more on social relationships especially listening and spending quality time with peers other than their parents or family. According to Erikson's, if an adolescent does not successfully achieve this stage, there is confusion regarding one's identity (Lumen, 2021). Parents have a responsibility to pay attention to the changes happening in their teens life distinguishing the ones that may be stressful and depressing, and support them to process their feelings or behaviours; encourage their adolescent to be involved in activities with fellow teens like sports, music and theatre; listen and respect their opinions (Centre for Disease Control, 2020).

AYC may not receive support because they are taken up by the caring and the person who is supposed to support them is the one whom he or she is caring for. This leaves them with the dilemma as they try to establish their own ways of surviving through the changes. The lockdown measures due to covid19 makes the family almost the safest



place for AYC leaving them with no chance to escape from their caring roles even if just for a little while. While previous studies shows that some young carers develop internal positive ways of dealing with their stresses that eventually prepares them for adulthood (Save the children, 2010; Robson et al 2006; Bjorgvinsdottir and Halldorsdottir, 2013), most young carers struggle significantly to balance caring roles and their psychosocial needs thus requiring support to enable them thrive (Aldridge 2019; Leu and Aldridge 2017; Abraham and Aldridge, 2010). The psychosocial needs in this context refers to the need to associate with friends, to be heard, to feel loved and accepted by peers, decision making, independence, need for approval, to have quality sleep etcetera (Ministry of Gender, Labor and Social Development, Uganda, 2015) . This research investigated the feasibility of using a Whole-Family Approach Model in addressing the psychosocial needs of adolescent young carers in the context of covid19 pandemic which focuses on identifying strengths within the family and members developing strategies together to address the needs.

### 1.3 Research aims and objectives

#### 1.3.1 The main aim of the Study is;

To determine the feasibility of a whole-family approach in responding to the psychosocial needs of adolescent young carers during time of COVID -19.

#### 1.3.2 Specific objectives:

1. To examine the perception of social service workers on adolescent young carers needs during COVID-19 pandemic.
2. To analyse the perception of social service workers on using the whole-family approach to respond to the psychosocial needs of adolescent young carers during COVID-19 pandemic.
3. To examine the perceived barriers in using the whole-family Approach to respond to the psychosocial needs of adolescent young carers during COVID-19 pandemic.

4. To identify strategies to address the perceived barriers in using the whole-family approach to respond to the psychosocial needs of adolescent young carers during COVID-19 pandemic.

#### 1.4 Main research question

How social service workers see the usefulness/relevance of WHA model in response to the psychosocial needs of adolescent young carers during COVID-19 pandemic?

##### 1.4.1 Sub questions:

1. How do social service workers perceive the psychosocial needs of adolescent young carers and how these needs change during COVID-19 pandemic, in their opinion?
2. How do social service workers perceive the whole-family model relevance in responding to the psychosocial needs of adolescent young carers in Lira during COVID-19 pandemic?
3. What are the perceived barriers/potential in using the whole-family approach to respond to the psychosocial needs of adolescent young carers in Lira during COVID-19 pandemic?
4. How do social service workers address the barriers/potential encountered in using the whole-family approach to respond to the psychosocial needs of adolescent young carers in Lira during COVID-19 pandemic?

#### 1.5 Significance of the study

This study and its findings are significant to social workers, adolescent young carers and policy makers in the following ways. Hypothetically, the research intends to explore the perspectives of social workers on the psychosocial needs of adolescent young carers and the whole family approach model in the context of COVID-19 pandemic. Such discussions provides a ground to advance discussions on adolescent young carers more specifically during pandemics and how social workers and other services providers should be prepared to respond to their psychosocial needs. The increased level of awareness among social workers also enables them advocate for and develop context based support for the young carers. Secondly, it will inform policy

decisions on what services and methodologies are most appropriate for young carers during pandemics in the district and national level. Additionally, the study contributes to the body of knowledge by bringing in more insights about Adolescent young carers and how genders norms shape their care responsibilities. Such findings will enrich social work practice and forms a basis for better service provision to AYC and preparation of adopting/changing models during abnormal situations.

## CHAPTER TWO

## 2.0 Literature review

In this chapter, three main sections will be explained based on the research questions. First we shall the perceived psychosocial needs of adolescent young carers by social service workers, the perceived knowledge of the whole family approach model in responding to the psychosocial needs of adolescent young carers and the perceived barriers to addressing the psychosocial needs of service user. Then we shall discuss the perceived strategies for addressing the barriers encountered in using the whole family approach model in responding to the changing psychosocial needs of adolescent young carers. From the discussions, a theoretical framework will be generated.

**2.1 The perceived psychosocial needs of adolescent young carers based on the social workers.**

Globally, countries are at different levels of awareness and recognition of young carers in general with United Kingdom taking lead (Aldridge 2018; Joseph et al; 2019). Other countries like Sweden, Norway, Canada, New Zealand, Switzerland, Austria, Germany and France follows after UK with awareness and policy processes even though they are all at different levels (Becker and Leu, 2017). Studies conducted on young carers demonstrate significant increase in the level of awareness and recognition of young carers particularly with the health and education professionals but limited among social workers and yet they are the ones most likely to be working with such families more often. (Becker et al, 2019; Frech et al 2019; Aldridge 2018; Bjontegaard et al, 2018; Cohen et al 2016; Save the Children, 2010; Robson et al 2006). A 2016 country wide study conducted in Switzerland showed that the level of familiarity of the term young carers was higher among health and education professionals and quite low among social service professionals and yet the latter associated the issue of young carers to be more relevant to their work (Becker et al 2019a). Frech et al brings to the discussion the use of the terminology of young carers. According to a study they conducted in Germany, the concept was interpreted differently among professionals. They suggested the need to contextualize the

definition for easy identification of the young carers (Frech et al, 2019). Nevertheless, a universal definition is crucial for coherence (Cheung et al 2003; Becker and Leu 2017; Aldridge and Becker 2017). A study conducted in Uganda shows limited awareness among professionals and lack of institutional support to the children. the lack of national data and limited information among social workers may continue to affect response to adolescent young carers. (Becker et al, 2007; Aldridge 2019). A key recommendation was for advocacy at different levels for recognition and support to adolescent young carers (save the children, 2010).

Aldrige relates to the care act 2014 which states that young carers are children first and therefore identification of their needs in a timely manner could facilitate improved support services for them (Aldrige 2018). In regard to the psychosocial needs of the adolescent young carers studies reports that young carers have social, psychological and emotional needs (Aldrige 2020) that if they are not met can affect their potential to learn and achieve in future (Aldrige 2020, Banks et al., 2002; (Nagl-Cupal et al.,2014). Socially, they feel the need for family whom they can depend on whenever needed, the need for friends who are understanding of the situation and can form peer support, the need to participate in school activities and develop their abilities, the need for religion, culture and community where they belong to (Uganda Ministry of Gender Labour and Social Development, 2015). This gives them the fulfilment of accomplishments as full members of their communities. Psychologically the need for spiritual guidance, respect, recognition and some level of independence to explore the world and be who they want to be (Collins and Bayless, 2013). They also need parental love and care and love and companionship from partners. They feel the need to desperately fit in a group, the urge to do what the other peers are doing (Nagl-Cupal et al.,2014; Save the Children, 2010)

## **2.2 The perception of social service workers on using whole-family approach in responding to the psychosocial needs of adolescent young carers during covid-19 pandemic**

While responding to HIV and AIDS pandemic in Uganda, the WHA was encouraged due to its nature of provision of holistic support to members of the households building

on their individual strengths (Richtcher, 2010). According to this approach, the family is the basic unit that should provide care and support to its children and members of the household and that makes copying more easier than services provided in silos (Richtcher, 2010). UK policy makers, particularly those in the Children's Society (Frank, 2002), the Princess Royal Trust for Carers and the Disabled Parent's Network have played a major role in developing the model for this holistic approach to service delivery, and it seems to have been working well in responding to the need of the young carers. Besides the fact that it encompasses everyone in the family makes it more appreciated (Aldridge 2018; Keith and Morris, 1995; Newman, 2002; Wates, 2002). The WFAM is linked to the family systems theory whose goal is to improve clear communication of a family unit.

*"It's typically applied to treat psychological conditions in children and adolescents. It also works to better the overall mental health and emotional problems of all members of the family" (Watson, 2012).*

There is need to understand its suitability in responding to the psychosocial needs of AYC in the Ugandan context during covid19 pandemic.

### **2.3 Perceived barriers in using the whole-family approach**

Cultural barriers could be a significant barrier to WHA. Some families may be practicing negative cultures that infringes on the rights of the AYC for example early marriage, female genital mutilation, and for that reason, they do not want to have the issues exposed to outsiders like social workers who works to safeguard and protect children. Entry into such a family may be difficult and requires long term interventions that focuses on attitude change. Secondly, inappropriate and uncoordinated family based interventions (Aldridge et al, 2016) that leaves members of the family with limited options in regard to their situation. Thirdly, stigma associated with caring and the condition of the sick person. Some families do not like their children to be identified as young carers due to fear of what the reaction from the society will be and as a result, they end up failing to provide information to the social workers that could have been used to support them. Structural and systemic failings also contribute to this problem (Aldridge et al, 2016).

## **2.4 Strategies to address the potential barriers encountered by social service workers in using the whole-family approach**

Building capacities of social workers on the WFA to deal with cultural dilemmas within the families. There is need to build the capacities of social workers to understand and plan for family support (Aldridge 2016; Nap et al, 2020). Once the social workers are empowered, they will give relevant information to the household members so that they get to appreciate the roles adolescents play and giving them chance to experience being an adolescent first because they have the right to do so (Becker et al, 2020). Keep communication flow in the family encourages openness by family members to each other and social workers. Aldridge (2018) suggests that focus should be on preventative aspects by ensuring consistency during needs assessments and thorough screening of AYC. Similarly, the need to move away from victimizing young carers to supporting them to deal with stress that comes as a result of informal caring (Joseph et al, 2019) have the potential of making WHA more successful. In addition, a multidisciplinary working and awareness because issues of young caring cuts across disciplines (Aldridge 2019; Nap et al, 2020).

## **2.5 THEORETICAL FRAMEWORK BASED ON THE FAMILY SYSTEMS THEORY AND RIGHTS APPROACH IN RELATIONS TO THE PSYCHOSOCIAL NEEDS OF ADOLESCENT YOUNG CARERS**

### **2.5.0 Child rights approach to understanding the care roles performed by adolescent young carers.**

Children all over the world are entitled to enjoy their childhood because it is their right to do so. This is categorically stipulated in the international and national legislations specifically the convention on the rights of the child (United Nations, 1989) which sets a bench mark upon which state parties should work to ensure that those rights becomes a reality to every child. However, such enjoyment is curtailed for some children as they are pushed to the edge by circumstances affecting their loved ones who may be chronically ill, have a disability, is mentally ill or taking care of their siblings due to death of their parents or caregivers. A study conducted by Aldridge suggests that young carers are children first and thus there is need to address to their needs as

children. A recent study conducted in Europe highlights diverging views regarding legislations to support young carers (Nap et al, 2020). The study highlights the importance of specific legislation to formalize the rights of YCs. The study suggests that future studies with policy makers so as to gain insights into the different policies between countries to extract best practices to build better policies to support YC in Europe (Nap et al, 2020). I think the dilemma for policy makers is whether children should be completely safeguarded from care functions or to what extent they should perform the caring roles?

In a recent study one of carers expressed that her parent didn't want her to be referred to as a young carer because it made her feel less of a parent to her daughter (Blakeholmes, 2020). If such children are not supported, the effects could be devastating for them in the long run. And that is probably why YCs continues to be a hidden category of children.

### **2.5.1 UNDERSTANDING THE PSYCHOSOCIAL NEEDS OF ADOLESCENT YOUNG CARERS THROUGH THE SYSTEMS THEORY**

The systems theory is associated with Niklas Luhmann a German sociologists whose writings shaped the development the theory. The argument by critics is that the systems theory is complex and yet crucial in analysing the society. According to Luhmann, the systems look at interactions within families and organisations and functional systems as important. As such, it is rather fragmented into politics, religion, economics, law, health, and none of them is dominant as each of them wants to fulfil its own purpose (Mik-Meyer and Villadsen, 2013). The systems theory is one of the theories used in social work practice that bases on the idea that behaviour is influenced by a variety of factors that work together as a system such as family, friends, social settings, economic class, and the environment (Mik-Meyer, N. and Villadsen, K., 2013; Payne 2014). *It offers a more complete view of a person's situation within his or her social environment* (Social work license map, 2021). In reference to the works of Milan, the theory has three broad schools of intervention that includes structural approaches, strategic approaches, and systemic approaches (Mackinnon, L and James, K, 1987). For the purposes of this research, the systemic approach will be delved into deeper to provide a basis for analysis of the findings from the field.



### 2.5.1.0 Systemic approach

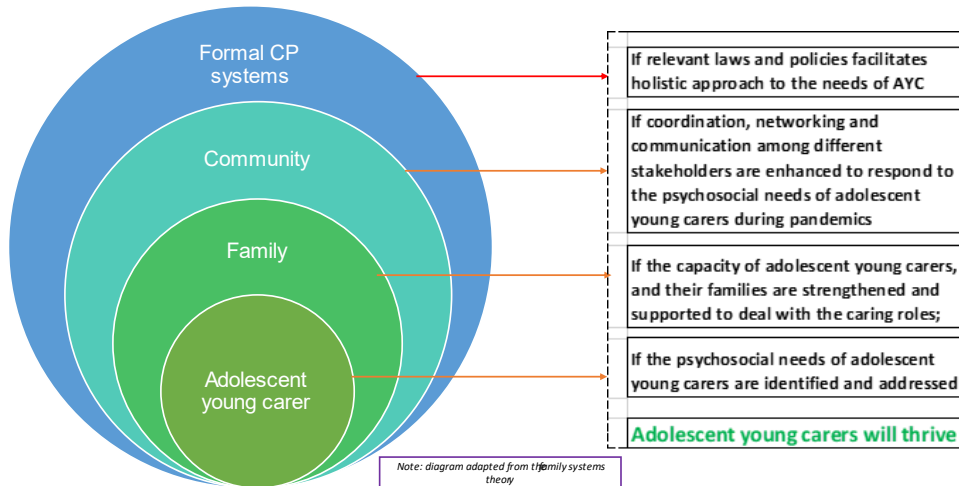
The systemic approach is an intervention model that works with the whole family and factors in the environment influencing their behaviours and patterns (Mackinnon, L and James, K, 1987). This assumes that whatever affects an individual is likely to have implication to every other individual within a family but also with members of the extended family, neighbours, schools, hospitals, churches, and all that is within the environment. So, for a problem to be addressed all that is within the environment need to play a role to it. Through the systems approach, social workers can explore an individual's story and try to generate meaning or understanding of the entire environment to provide appropriate service to them (Mackinnon, L and James, K, 1987).

Over the years Uganda has been advocating for and working through a systems approach to child protection and the adolescent young carers fall within the category of children to benefit from a functional system. It puts greater focus on prevention and strengthens the critical roles of key actors including government, civil society, parents, caregivers, families and other community structures that work together to provide protection mechanisms and services (Government of Uganda, 2020). In building strong linkages between the different actors, the aspects of coordination, cooperation and communication is critical (Mackinnon, L and James, K, 1987) but due to the pandemic, these functions have been challenged.

Luhmman views the society as a set of systems of communication with many complexities (Mik-Meyer and Villadsen, 2013). If that is the case, then elements within the system should effectively communicate to address problems within the society. In the context of covid19 pandemic, lockdown measures have been enforced and people are confined and that has caused a disruption in the way systems have been operating. For the adolescent young carers literature suggests a possible increase in their psychosocial needs (Blake-Holmes, 2020, UNFPA, 2020) and my research looks at responding to their needs through a whole family approach model. Previous literature argues that young carers are most often invisible (Robson et al, 2006) and therefore failure to effectively communicate to them during the pandemic could worsen their situation (MGLSD and UNICEF 2015). The question then is how prepared were social workers for this sudden shut down and what new strategies do they have to

perform their functions during such a pandemic? The study is suggestive that the whole family approach model is useful under normal circumstances but during this pandemic, the community support structures approach was more relevant in filling the gaps in services.

## THEORETICAL FRAMEWORK



9-Jun-21

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## 2.6 RELEVANCE OF RESEARCH FOR INTERNATIONAL SOCIAL WORK

The growing debate among researchers and practitioners has led to significant increase in the awareness about adolescent young carers around the world. While countries are not at the same level with recognition and development of interventions for this category of children, there is a recognition that the young carers are in every country of the world and they contribute immensely to care. The roles they perform has lasting impacts on them and that is why identifying their psychosocial needs and working with them to address those needs are critical for social workers. Evidently, these adolescent young carers may not completely stop their caring roles because of different factors but it should not be forgotten that they are children first. Social workers should position themselves to disrupt the normalization of their conditions and ensure that their concerns are documented and responded to using relevant approaches.

one of the critical discussions in social work at the international level today is the tension between the fundamental rights versus cultural relativism (Healy, 2007) and its effect on the service users. During the study, it was discovered that culture played a significant role in shaping the caring roles played by adolescent young carers. The common practice in this community was that when a parent dies, automatically the older child takes up the role of heading the family. Compared to the past, the extended families would take up the role of the family but due to the breakdown in the social network, such support is dwindling progressively. But also linked to this is that children are brought up to understand that if their parents became terminally ill or die, the eldest child automatically takes up the leadership of the family irrespective of their age. While for the older children, it is more realistic but for the adolescent young carers, the burden maybe challenging for them. This is due to the fact that they are still children so although culturally it is expected of them to do so, how does that correspond with aspect of rights as depicted in the international legal instruments such as the united nations convention on the rights of the child (UNCRC, 1989)? As seen from the discussions there is need for social work while observing the positive tenants of culture, those that infringe on the universality of rights should be addressed in practice. Ethical social work practice would promote universal rights while supporting the preservation of culture whenever possible (Healy 2007)

**User voices into policy decisions that affect them:** so far, there seem to be no study done globally about adolescent young carers except for a few country specific studies. The fact that such a study is non-existent is indicative that policy makers may not prioritise the issues of adolescent young carers in policy decisions and yet their voices matters. Borrowing the phrase from the disability group “nothing about us without us”, social work need sufficient information from the adolescent young carers especially their lived experiences so that the issues are periodically tabled to influence policy decisions globally. Fundamentally social work practice is about social justice and social change and this is reflected in the meaningful involvement of service users and that is why social workers should advocate for to their voices to be heard during policy decisions. This would contribute to addressing the challenge of Invisibility of young carers in policy. Listening to the adolescent young carers must be embedded in every discussions and should be a continuous process of advocacy.

**Equipping social workers with relevant skills to work with future pandemic through capacity building, mentorships and coaching.** One of the key points of reflection among the social workers was the position of social work or social services during the pandemic. As clearly seen, social service work was not prioritised in the beginning of the pandemic and that left young carers without psychosocial needs unattended to. According to the respondents this was a huge oversight that was only realised after several cases of violence against children was coming up through the media. Looking at the nature of the pandemic, the manner in which people are restricted from their usual routines and living in isolation there was increased anxiety and fear that required psychosocial interventions instantly but failure to treat such services as essential led to more frustrations with the people. It is in the view of the researcher that such crucial support services be considered as essential so that social workers will not have to intervene after damage is already caused. Practitioners could consider such services integrated within health services. But for that to happen there is need for multi sectoral approach to responding to future pandemics and that goes hand in hand with resource allocation.

## CHAPTER THREE

**3.0 METHODOLOGY**

In this chapter, the researcher presents details of how the study was conducted. Specifically, the design, scope of study, study population, sample size and sampling techniques, the data collection methods applied.

**3.1 Research design**

A research design is the entire general strategy that one chooses to mix different components of the study in a coherent and logical manner so as to effectively address the research problem (Lecture notes, 2020). Described as a “blue print” for research (Yin, 2003), research design focuses on addressing what questions to study, which data is relevant, what data to collect and how the data would be analysed. For this study, the researcher adopted a qualitative research design which aims to answer the why and how questions to generate meanings and interpretations that came from the field (Tracy, 2013). The methodology was selected because of its descriptive nature and the flexibility to examine opinions, thoughts and feelings of participants about a topic (Punch, 2013). Qualitative research design enables people “*to understand the world, the society and its institutions*” (Tracy, 2013) and since the roles of adolescent young carers are often taken for granted, the chosen method was relevant to facilitate reflections and make meaning out of it. The study employed a case study approach (Yin, 2003 and Stake, 1995), an approach used in qualitative research where the investigator explores a bounded system or multiple bounded systems over a period of time through detailed data collection (Punch, 2013; Tracy, 2013) and with multiple sources of information (Creswell, et al, 2007). The theoretical underpinnings of the method is based on the constructivist claims of Robert Yin and Robert Stakes that truth is relative and it is dependent on one’s perspective about a phenomena (Stakes 1995 and Yin 2003). The researcher employed two main qualitative data collection tools that is case studies from the lived experiences of adolescent young carers and semi structured interviews with social workers, and the social service workers working in the NGO sector and at the local government department in Lira district.

**4.2 Study population**

The study participants comprised of adolescent young carers. These young carers did not participate directly but rather indirectly through the social workers. After briefing the social workers from TPO Uganda about the need to involve the adolescent young carers in the study, they confirmed that there were AYC's whose stories could be documented and shared with the researcher and so the AYC's stories based on their lived experiences were compiled by the social workers for this research. This study directly targeted the social workers from TPO Uganda, selected technical staff from the community services department of Lira district Local government and representatives at the sub county levels. All these staffs have been directly or indirectly working with adolescent young carers in their different capacities.

### **4.3 Sample size and selection techniques**

The study population was selected from Ogur, Agweng, Aromo, Agali and adekokwok sub counties in Lira district. Other key informants were selected from community services department at the district level. At the beginning, social workers from TPO Uganda were briefed and asked to document case studies of the adolescent young carers whom they have been working with and a total of three case studies were submitted to the researcher, reviewed and confirmed. The case studies facilitated the development of interview guide for the social workers and the social service workers. Purposive sampling, a non-probability technique was used to select participants because of its strategy of selecting participants with in-depth information about the goals and purpose of a research (Punch 2013). For faster response from the participants, snowball sampling method was used to get respondents. This method is known for being cost effective because the referrals are got from the primary data source. It is also noted that some people do not want to come out and participate in research but if someone who they know reaches out to them then they can participate in the research. During our study, the lead social worker recommended 4 social workers who produced the case studies and they too accepted to participate in the interviews. Similarly, the probation and social welfare officer was interviewed and later suggested that the community development officers at sub county level could participate in the study and indeed they were interviewed. All those recommended were found to be relevant and they provided substantive information for the research.

### **3.4 Data sources**

Primary data was collected through the case studies of adolescent young carers compiled by the social workers and semi-structured interviews with social workers of TPO Uganda and social service workers of Lira district local government. Each semi structured interview was approximately an hour long and each interviewee consented to participate in the interview. While 6 interviews were conducted face to face, 3 interviews were conducted through the mobile phone at the request of the respondent. All interviews were recorded on the mobile phone after getting consent from the interviewees and the researcher was able to transcribe, code and derive themes from it. Relevant literature from text books, academic journals, reports documents from google scholar, Lincoln University Library, teaching notes from advances lectures and those from the government of Uganda websites were utilised as secondary data sources to supplement the findings.

### **3.5 Data collection methods**

#### **3.5.1 Case studies**

In this study, the researcher started by having an interaction with social workers from TPO Uganda who directly implement interventions in the sub counties of Adekokwok, Agweng, Ogur in Lira district. After briefing them about the research, they had the opportunity to ask all necessary questions regarding the study and they gave their consent to identify specific cases of adolescent young carers from their interventions and document their stories for the purpose of this research. A total of four cases were submitted but only three were considered by the researcher because they were more relevant to the study based on the case study guide that was shared with them. The selected three cases were reviewed by the researcher and sent back to the social workers to make amends to aspects of the cases that was lacking information and yet the info was crucial for the study. After the back and forth feedback through email communication, final version of the cases were confirmed and submitted to the researcher for consideration. The case studies provided data based on the lived experiences of the adolescent young carers and some accounts from the social workers who have been working with them. Based on the case studies, questions were derived for the semi structured interviews whose respondents were the social workers and the social service workers.



### **3.5.2 Semi-structured interviews with individuals**

Further information about the adolescent young carers were gathered from the social workers through the semi-structured interviews. A total of 3 social workers and 1 coordinator was interviewed from TPO Uganda. Based on their knowledge of the coordination mechanisms within the district, they recommended one of the probation officers who was working closely with them from community services department and the respondent provided significant information related to young carers, policy issues and the approaches they have been using to reach out to them during covid-19 pandemic. The researcher also interviewed the senior probation and welfare officer who consequently endorsed the sub county community development officers who are at the forefront identifying and supporting adolescent young carers to be interviewed. In total 9 participants were interviewed including 3 social workers from TPO Uganda, 2 participants from probation and welfare office and 4 community development officers at sub county level. Their consent were sought for prior to the interviews and reassurance of all the ethical considerations took place and they were also given the opportunity to seek for clarity where they did not understand. The interviewees were reassured of their right to leave at will if they did not want to participate in the interviews anymore but all the nine completed the interviews. Altogether, six participants were interviewed face to face and three of them participated through the mobile phone based on what was most suitable for them. These interviews were recorded in agreement with the respondents and that made it easier for the researcher to transcribe, code and derive themes from the data collected. Hand written notes was also taken into consideration as a backup.

## **4.0 Data processing and analysis**

The researcher was responsible for the data analysis, interpretation and presentation of the findings. For the purpose of analyzing the data, inductive analytical strategy was selected because it gets a researcher to the starting point which fuels the exploration into the subject matter to understand how accurate or inaccurate the initial



assessments and inferences have been (Punch 2013, Reichertz, 2013). Therefore, data collected from the semi-structured interviews and the case studies went through the process of 1) transcription whereby the recorded interviews were repeatedly listened to and the text transferred onto paper. This was done to enable the researcher understand what they were saying and what was central about the conversation. 2) it then went through the coding process whereby data was broken down into bits of information and assigned into categories or themes 3) the categories enabled the researcher to formulate central themes which were then given short descriptions and linked with illustrative citations from the interviews (Lecture notes, 2020). These are the themes that the reader will interact more with in chapter four of this report.

## **5.0 Ethical considerations**

In every study, there are ethical dilemmas that according to Sobocan et al (2019) are inherent throughout the research process from identification for what to study until dissemination of findings. With reference to our research, informed consent, confidentiality, privacy and doing no harm were taken into consideration throughout the study. Informed consent is the process where the researcher obtains permission of the participants to take part in the research. Before obtaining consent, the researcher should have provided relevant information to the subjects so that they understand and seek for clarity whenever needed so that they can decide whether to participate or not. Obtaining consent is important because it ensure protection for the rights of the participants, they become aware of what the data will be used for whether in the present or future. The consent can be obtained orally obtained or in a written form depending on the type of research and participants. For our study, the participants were people who could read and write so a written consent form was developed by the researcher and confirmed by the supervisor. At the beginning of each interview, the researcher gave time for the interviewee to read through the content followed by an explanation by the investigator. We then gave time for the interviewee to ask clarifying questions which were all attended to and interviewees were reassured of their freedom to exit the interviewee at will. Since the researcher needed to record the proceedings, a statement was included in the consent form reassuring them of the privacy of the information that was signed by the respondents.

The recorded interview enabled the researcher to capture the exact words from the respondents which made the research more authentic.

Throughout the research, the respondents were reassured of confidentiality of the interview and the information obtained from the interviews. Confidentiality is founded on the principle of respect and autonomy which implies that the information that was collected from the participants should not be disclosed without the knowledge and permission of the respondents (Lecture notes, 2020). It is based on this notion that the respondents who participated in our research were reassured of the privacy of the information. First and foremost, the case studies were documented without the actual names of the adolescent young carers and instead pseudo names were used. They were also allocated numbers 1-3 and it is the numbers that were used in the section of findings. For the semi-structured interviews, only the titles were captured in the transcripts and they too were allocated numbers to distinguish them from each respondent. All these were attempts to keep the personal information about the respondents secured. The researcher was mindful of the preference of where and when to do the interviews, and was flexible to adjust to suit the respondents. For example one interviewee chose to be interviewed away from their office setting to limit interruptions, five were interviewed from their offices and three preferred being interviewed on phone at a convenient time though they signed the consent forms physically. They all agreed to have their information shared for the purposes of this research as explained by the researcher.

## **6.0 Study Limitations**

Just like many other studies, there were limitations observed in our study. First of all, the study had a small sample scale of only 9 participants and the geographical scope was also limited which was sufficient for this study and allowed for saturation of responses but it is possible that some key participants could have been left out in the process especially those who were not working so closely with TPO Uganda and yet have been providing services to the AYCs. Secondly, due to covid19 pandemic, the researcher could not carry out focused group discussions with community reference groups, a group that was recommended to be very critical in providing support during the covid19 pandemic. This was because there was significant increase in the number of covid19 cases that eventually pushed the country a nation-wide lockdown and so it

was not possible to access these groups. Similarly, the social workers had challenges reaching out to the adolescent young carers to track their progress when they were developing the case studies. The nature of the pandemic also limited the researchers choice of respondents and yet initially, the researcher had planned on involving the adolescent young carers more in the study but this was not possible. In addition, the study analysis of the psychosocial needs of adolescent young carers through the child rights and the systems theory framework was quite useful however there could be other theories that may be more relevant to the study that needs to be explored in the future.

## **7.0 Dissemination**

The researcher intends to share findings from the research with different participants of the study. Firstly, the social workers at district and sub county levels who participated in the interviews will receive a copy of the findings on their personal emails so that they can read and give feedback to the researcher. For those who worked on the case studies with the young carers, they will also be encouraged to share the findings with the adolescent young carers for them to appreciate and acknowledge their contribution to the research. With keen considerations to the privacy of the participants, the research findings is due for presentation before the Advances team including the professors and students who have been part of the process of the development of this research from the beginning to the end. The researcher is also looking forward to publishing an article about this project on through the polish journals and possibly social work journals at national and international levels to increase awareness about adolescent young carers and inform policy formulations.

## CHAPTER FOUR

## 4.0 PRESENTATION OF FINDINGS

**4.1 Introduction**

This chapter presents the study findings regarding the psychosocial needs of adolescent young carers and the Whole Family Approach model relevance in the times of covid19 pandemic as revealed by the respondents during the study. The findings are based on case studies got from three (03) adolescent young carers and information gathered from the nine (9) key respondents from TPO Uganda and Lira district local government.

**4.2 Data presentation**

Data presentation was done in accordance with basic principles in research. Qualitative data collected through case studies and informant interviews was summarized as statements from the respondents. The researcher used inductive approach in the analysis whereby similarities between cases were developed into ideas and eventually finding central themes that informed the report. This made it possible to verify all information that was captured, and that the coding addressed the research questions. Based on our findings, ten main themes related to the psychosocial needs of adolescent young carers and the whole family approach model during covid-19 pandemic were identified as presented below;

**4.2.1 The psychosocial needs of adolescent young carers (AYC): psychological and social needs and how they are linked to material needs.**

According to the study report, the social workers perceived two categories of psychosocial needs of adolescent young carers which had to do with the mind and their social environment that is the psychological and social needs. They suggested that these needs may not have been so different from what the young carers already felt before the pandemic but the intensity may have been felt more during the pandemic due to the isolation and confinement issues. In regard to the psychological needs, the interviewees cited the need for parental love, care and guidance were very significant and that such needs are considered critical for the cognitive development of the AYC's. One of the social workers said

*“...particularly the need to feel loved, to be cared for, the need for a place to belong and to have meaningful friendship and many others” (Probation and Social Welfare Officer 1).*

The participants mentioned that such needs of the AYCs were not being met because those who were supposed to give it to them are incapacitated by their conditions that is related to either being critically ill, mentally challenged among others. The submission of the PSWO 1 was confirmed by a statement from another participant who had this to say;

*“what I see from my sub county is that these children lack parental love and guidance and as you know when like they come to our offices we are not able to offer them such love but we can just support them by giving them hope and linking them to counselling support sessions” (Community Development Officer 3)*

In addition to the emotional needs mentioned above, the participants stated that the AYCs need for personal freedom to engage in activities that made them happy, they also need a sense of belonging and the ability to be independent and make their own choices in life. The inability of a young carer to experience all these could make them feel devastated and frustrated as these are not the same scenarios with other young people within their age group. And this corresponds with comment by Erikson's that if adolescents do not achieve their hopes and dreams at adolescents, they can be confused of who their identify is in the future (Lumen, 2012).

The participants also elaborated further on the social needs of AYC as another category of psychosocial needs. They frequently mentioned the need for the young carers to form meaningful friendships whom they can rely on, for peer support where they can share their lived experiences with them without feeling unwelcomed but instead they would feel accepted because of the similarities in their conditions, the need to be understood and have equal treatment; the need for a family to belong to and community support network as crucial for the adolescent young carers social development. Example of illustrating statement is quoted below.

*“so they need information on how they can cope, need for family support or guidance, to belong to a group especially with their peers, inspiration, sometimes*

*they need counselling services...” (Social worker 1)*

In their sessions with the adolescent young carers, the social workers explored some of the social needs of AYC's and this is what participant shared;

*“ However when asked about her own school needs, Akello broke down in tears saying that seeing her fellow friends join other institutions of learning was very painful because her dreams are shattered” (Social Worker 3)*

Based on the above statement, the findings are suggestive that even though the adolescent young carers are proud to support their siblings to for instance go to school, they experience such emotions that if left unattended, could cause psychological harm to them as expressed by the SW3.

The participants brought in to the discussion the complexity of the needs of the AYC highlighting how each of them led to the fulfilment of the other and that is why they most commonly mentioned the material needs before even mentioning the social and psychological needs. According to them material needs play very critical role in ensuring the psychosocial wellbeing of the service users.

*“Failure to address physical needs brings psychological problems and in psychosocial support addressing only one problem is not sufficient” (Community Development Officer 2)*

The submission by the respondents is revealing that meeting the psychological and social needs should not be viewed independently from the material needs especially the need for food, clothing, protection medical care and finances. Throughout the interviews, interviewees could not avoid mentioning such needs as a contributor to psychological distress for adolescent young carers that leads them to drop off school so as to search for food for the family.

*“Their biggest challenge is finding food. They are in a very vulnerable situation, whereby he/she will drop out of school and when it comes to issues of health it is a big challenge” (Community Development Officer 1).*

It is mostly for the material needs that adolescent young carers had to go and dig in

peoples garden, go for quarrying or performing other causal labour so as to provide most importantly food for the family.

*In times of covid-19 pandemic it is of so much importance to understand the various needs of these children specifically psychosocial needs. Seeing from what happened during the lockdown such needs are important and yet they are often times not considered as important. But that cannot be thought of independently from their material needs. Meaning that at such a time as this, all these needs should be prioritised” (Community Development Officer 3)*

#### 4.2.2 Social workers familiarity with the Whole Family Approach Model (WFAM)

The study findings is indicative that the participants had a fairer understanding of the whole family approach model even though their interpretations varied. They reflected that the model encompasses the social worker working with family members based on their individual strengths to identify and respond to challenges faced by young carers and their families. According to the participants such an approach was considered to be sustainable because it attempts to build the capacities of each member of the family to support each other in times of need. This makes young carers not to be viewed just as passive recipient of support but contributors to problem solving within the family bringing in the aspects of user participation in service delivery (Adams R, 2008). The participants also explained the WFAM linking it to working with the available resources highlighting that the model promotes a search through the family to identify existing resources that are later on built on to support the household. The little resource can be expanded on for greater gains of all members of the family. For example one participant had this to say.

*“The WFAM therefore entails identifying what each one can do within the family and building on those strengths for sustainability...” (social worker 2)*

Another respondent illustrated further with an example of how they carry out needs assessments and explore together with the family members the needed support based on the available resources within the household as below;



*“For example we always identify an individual child and through this child we try to understand the needs at the family level that is affecting the child and then we brainstorm with members of the family how they can best be supported building on the resources they have at family level. Support is sought from the extended family and the community too” (social worker 1)*

According to the respondents, the WFAM is holistic in nature and therefore very relevant in addressing the complex needs of the AYCs and their families. From their perspectives, young carers and their families have complex needs that requires the person as a whole not just one aspect of their needs. The model therefore considers identification and the provision of physical, emotional, social and spiritual needs of young carers and their families which should be done collectively. In addition, they stated that with the WFAM, it was much easier for members of the families to speak up about their challenges and they were much more open to receive support from the social workers and other service providers. The participants mentioned that in cases where there was child abuse especially defilement or rape or child marriages, families were not so open to talk about them with social workers because of the complexities involved in managing the cases and the legal implications.

*“If there's a challenge in the family don't look at only the particular child because there could be other underlying factors within the family that requires a holistic approach to addressing the challenge” (PSWO 2)*

### **4.2.3 The Whole Family Approach Model (WFAM) in the times of COVID-19 pandemic**

During the study, the interviewees stated that the way the whole family approach model works was through the collaborative effort of all stakeholders involved that is for instance the young carer, his or her family members and the social workers and other relevant service providers. Under normal circumstances they should meet regularly, plan, implement and review progress collectively however, this involvement was compromised in times of covid-19 pandemic. According to the participants almost all the resources was redirected to the health sector for responding to the pandemic leaving out the social support services including psychosocial support without clarity



of how the activities would be executed. The respondents also stated that, during covid-19 pandemic, there was a sudden shift in the way they responded to cases because of the nature of the disease. The lockdown measures put in place constrained social workers movement to the field, face to face interactions with families was not possible in a bid to limit the spread of the virus and yet young carers needed various kinds of support including psychosocial support services. For that reason, practitioners turned to “telecounseling” (Onyango and Veale, 2020) whereby they would use phones to reach out to the young carers and their families. However the telcounseling had limitations because not all young carers may have had access to a telephone, there were issues with connectivity due to poor network coverage, and lack of airtime to make phone calls. The other constraint was the aspects of privacy and confidentiality where a social worker needed to communicate to one carer through someone else’s phone and yet privacy is part of the ethical considerations in social work practice. Converging every family member over the phone was not practical and that made only emergency issues focused on saving lives to be addressed within the households. Therefore almost no attention was given to the completeness of a model as long as life was being saved. Therefore in their view the WFAM was inadequately applied and thus not fully relevant in responding to the psychosocial needs of adolescent young carers during covid-19 emergency.

*“Because of the restrictions, we were only specific to a particular case reported. Even if you go to the family you focus on how to address that particular problem reported and whether all family members were involved or not was not the issue.*

*The rest of the issues were not now emergency even up to now we are only responding to few cases that are reported as emergency...” (Probation and Social Welfare Officer 1).*

In the researchers view, the model is known and they promoted it during their interventions nonetheless there were challenges related to fully realizing the outcome of the model. One of the respondents suggested that if the government could have enough resources, the best way would be to provide all the needs of the adolescent young carers in a holistic manner (Health, education, shelter, food needs).

#### 4.2.4 Inability to access adolescent young carers and their families was presented as a barrier to using the WFAM during COVID-19 pandemic

The findings revealed that in March 2020, the government of Uganda announced its first nationwide lockdown as a strategy to reduce the spread of the virus. As a result most of the social services were not prioritised as one of the essential services. Such a move left a gap in linking services to the young people and adolescent young carers in the country. Consequently, the usual places where young people would meet were shut down without providing practical alternatives to them to meet their needs. As they retreated back to the family setting they were progressively keeping in the shadow and slowly disappearing from the scene where they could easily be attended to and supported. Inability to access the young carers and their families meant they could not have discussions at family level to track or monitor action points derived collectively during family conversations and in the same way they could not observe some of the changes happening with the young carers and how else they would love to be helped.

*“Unfortunately, some of the essential services like community services were not operating at the beginning and it has been very hard for those in need of psychosocial support to find help” (Probation and Social Welfare Officer 2)*

With such restrictions and staff working from home attention was focused on specific cases of emergency only (Onyango and Veale, 2020). The respondents expressed that whole family approach could not specifically attain its goals due to such a limitation. Therefore facilitating this approach was not fully practical.

*“Because of the restrictions, we were only specific to a particular case. Even if you go to the family you focus on how to address that particular problem reported, the rest of the issues were not now emergency even up to now we are only responding to few cases that are reported as emergency...” (Probation and Social Welfare Officer 1).*

#### 4.2.5 Ethical dilemmas faced by social workers during COVID-19 times that affected the use of the WFAM while working with AYC.

The findings also illustrated that while the mode of communication to AYC and their

families changed to more of social media, some ethical issues challenged the work of social workers especially confidentiality and privacy of the adolescent young carers. The respondents shared that when lockdown measures were imposed they had to devise new ways of reaching out to the marginalised groups who were in critical need for support and one of the ways was through the use of mobile phones. But the phones have had its own limitations for example most of the AYC's do not have access to phones so for them to be supported, they needed to connect through a community volunteer to convey their concerns to the social workers who were by then working from home. This means that the information they shared with the social worker would also be heard by the CSS member. For a few who may have had access to mobile phones, there were issues of poor network reception, lack of data for effective communication to take place. This also brings in the question of equity in service provision which seemed to be lacking among the service users.

*“We managed to communicate through the mobile phones but of course it was not easy because they could only reach those who had phones while people who didn't have phones were missing out. For those who did not have phones we had to speak with them through the community support structures but of course that had ethical gaps with privacy and confidentiality issues. We also noticed that we could not assess effectively the progress of the family through a phone conversation” (Social worker 4).*

The social workers also stated that with the phone conversations they were unable to evaluate the conditions of the adolescent young carers and their families based non verbal communication which are very crucial in case work. Another mode of communication was through the radio and similarly the question of accessibility by AYC was central. It was also noticed that while government and civil society promoted use of phone calls and radio programmes to disseminating information to the public, such information was more focused to preventing and responding to the pandemic but not addressing the psychosocial needs of the adolescent young carers.

*“during the period of the pandemic, most information and awareness programmes was transmitted through the radio but as you know such marginalised group of children do not even have access to radios meaning that they could have missed the*

*teachings over the radio. Besides, most of the information was about covid-19 pandemic and not their immediate psychosocial needs” (Probation and Social Welfare Officer 2)*

The findings highlights relevant attempts of reaching out to the AYC’s and their families especially for emergency support but it also draws attention to some of the ethical issues for example confidentiality and privacy of the young carers that could have been compromised and that conflicts the social work principles.

In the researchers view point, inconsistent information to and from the families could have led to the weak implementation of the model but also the ethical consideration could have been quite challenging to ensure it among the participants deeming it less effective during the pandemic.

#### **4.2.6 Lack of prioritisation psychosocial support services for adolescents as essential service during the pandemic by government.**

According to the respondents there were already challenges with resource allocation prior to the pandemic and the push has always been to work with the little they had to support marginalised groups as much as possible. And so they had always attempted to work with the family to address the most urgent need. The concern on allocation of the limited resources was even intensified during the pandemic as much of the funds were redirected at responding to COVID-19 disease. As a result, all other support services that are crucial for children and adolescent development were almost put on halt. Such diversion did not only happen with the government programmes but also with services delivered by the civil society organisations.

*“..Even if the partners would go to the field, they would only stop at the sub county and shifted their focus onto providing sanitizers, handwashing facilities, distributing masks at the boreholes and at health centres (Community Development Officer 4).*

Interestingly, they brought up the issue of the presidential campaigns that eventually took a centre stage during such a time and instead resources were diverted for the political campaigns at the expense of other most needed social services like provision of psychosocial support. Thus politicians were up and about soliciting for votes while

other critical services to children and adolescents were still compromised. To the respondents, this was an issue of prioritisation and even though Uganda has the youngest population, children and youth services are least prioritised and budgeted for (Government of Uganda, 2020- Youth policy) and that is a challenge in realising the goals that are set by and for adolescent young carers and their families.

*“sometimes because issues of children and youth may not be a priority, you do not find resources to implement activities. So during COVID-19 lockdown and restrictions, the money that came was given to other areas so you remain in office but you cannot perform” (Probation and Social Welfare Officer 2).*

As seen from the respondents, they were suggestive of that fact that resource allocation contributes significantly to the success of a model and that has connotations with how leadership prioritises interventions. Social services being least of a priority during the pandemic slowed down interventions at the family level that could have been offered by resource persons to enhance the psychosocial wellbeing of family members of adolescent young carers.

*“Unfortunately, people want to commit money to tangible things like roads and buildings but not children’s issues that has to do with processes and systems” (Probation and Social Welfare Officer 1).*

#### **4.2.7 Limitations in coordination and networking among different stakeholders working in the district during the pandemic to facilitate the usefulness of WFAM**

Further findings also demonstrated that adolescent young carers have multiple and complex needs that requires functional coordination mechanisms to be in place but the sudden happenings of the pandemic found partners ill prepared for emergency response and that created a gap in services especially at the onset of the pandemic with tough lockdown measures. Some areas have only a few number of partners working with the government counterparts and they are unable to meet such needs of the young carers as stated by one of the participants.

*“...but of course there are some challenges. Only that such households have many needs and you may try to handle one of the needs yet there are also other needs*

*and where do you refer them to? Looking at agali, there are few partners so meeting all the needs at once is a challenge”(Community Development Officer 1).*

Participants elaborated that even the few partners may not be covering the entire sub county and most often not so flexible to deviate from their specific areas of interventions. For example one partner may offer psychosocial support services like TPO Uganda but then they do not provide food or education support. So how should such needs be responded to if there are no interventions targeting them.

*“Sometimes you may refer a child to a partner and that is not their priority areas (Community Development Officer 2)”*

They shared that even if they supported the psychological and social needs of the young carers and yet the other physical needs are not met that challenges the model’s success. Typical example was that young carers were willing to send their siblings to school after offering them emotional support but because the school required scholastic materials, some of the young carers could not afford hence some children missed returning to school when schools were re-opened.

*“Of course government is saying we have universal primary education (UPE) but there is that money that the school is asking for and such a family may not afford, health related issues, going to the health centres and there is no medicine” (Community Development Officer 3)*

*“The referral for the different services is a big challenge. They say use the opportunity of the existing programmes but existing programmes also have their own guidelines but we try as much as possible” (Community Development Officer 1)*

The study showed generally that there was a challenge with the functionality of the referral pathway as a result of the lockdown and yet the WFAM works effectively with a well-coordinated systems of referral. It was not possible for partners to meet and review cases as previously done in normal circumstances though at some point meetings were held on zoom to address most pressing problems.

#### **4.2.8 Increased utilisation of mobile phones and radio programmes as a strategy to addressing barriers encountered in using the WFAM.**

Even though the respondents presented the use of phones and radios with limitation in point 4.5 above, they demonstrated that there were more benefits to using them during the pandemic. Based on their responses, when social workers and other services providers could not conduct their routine activities with the adolescent young carers, they had to devise other mechanisms of reaching out to them and key to that was the use of the mobile phones. The increased utilisation of the mobile phones enabled them to communicate with young carers who needed emergency support. The interviewees noted that even though all members of the family could be reached through the phone conversation, it facilitated linkages with services at the community level for the most urgent problem to be addressed.

*“But during COVID-19 because of the restricted movements we adopted another method of reporting, most of the cases were coming through the child helpline. We have a toll free line called the Uganda child helpline, it's 116 so most of the people now adopted that because you cannot move to reach a member of the CPC, you could not move to meet a parasocial worker or CDO so most of the people started calling the helpline” (Probation And Social Welfare Officer 2)*

As seen in the quotation from the PSWO 2, the respondents stated that there was increased awareness and utilisation of the Uganda child helpline 116 a toll free number that was introduced before the pandemic by the ministry of gender labour and social development to enable children report cases of abuse in the families and communities. Even though there is no specific evidence of how many adolescent young carers used the toll free line, the assumption is that it was open to every child in Uganda to report any challenge they faced so that someone could attend to their needs. Another device that gained utilisation during the pandemic was the radio due to its ability to transmit information to a wider coverage.

*“Later we changed the strategy to use of radios which enabled us to reach a bigger population” (social worker 4)*

Overall, the study confirmed that there was increment in the utilisation of the media in case management even though it did not clearly demonstrate how it facilitated the implementation of the WFAM.



## 4.2.9 The community support structures (CSS) bridged the gaps in provision of services to adolescent young carers during the pandemic

Almost all the respondents acknowledged that the community support structures were more relevant in responding to the needs of the young carers and other emerging issues within the community. In their views, members of the CSS came from the same communities where the AYCs were, they are familiar with the context and they are easily accessible by the adolescent young carers. Those CSS who were frequently talked about by the participants included the Child Protection Committees (CPCs, the parasocial workers, Village Health Teams (VHTs), and Local Councils 1 (LC1). Because of their position in the society, their work is highly valued and appreciated and it is for that reason that they were in position to bridge the gaps during the pandemic.

*“We then came up with a plan of strengthening the CPCs together with the VHTs to monitor activities at that level and report to the CDO” (Community Development Officer 1)*

*“You will also realise that most of the emergency cases were attended to by the community structures like the CPCs, village health teams and local councils, parasocial workers, Parish Development Committees (PDCs)” (Community Development Officer 2)*

In the view of the researcher, the role of the community support structures plays significant role in the identification, support and referral of the protection cases within the community and therefore concerns of adolescent young carers would be known to them and it could be more sustainable to work with them to facilitate dialogue at household level.

## 4.2.10 Advocacy for psychosocial support services to be considered as essential service during the pandemic.

The study findings shows that during pandemics such as covid-19, governments and structures on ground may focus their attention on the most obvious support services such as health and yet the trauma one goes through during the course of a pandemic



may have even greater effect on their health seeking habits. As seen from the study it was not until there was a sudden increase in the number of protection and gender based violence cases at the community level that stakeholders began to advocate for psychosocial workers to be considered as essential staff almost three months down into the lockdown due to the pandemic. This came through reports on radio programmes and phone calls reporting cases that needed referral and yet there were no services available for them on ground. Such concerns placed much pressure on government to revisit its list of services that were considered essential and eventually social services was considered among the essential services. The radio became a forum for advocacy for reinstating some of the services including psychosocial support services for children and adolescents. Some of the respondents suggested that government could consider providing holistic interventions so that it is much easier to realise the outcome at family level.

*“..the suggestion would be that if government could try to bring in all the packages, to individual households. So that when you go to the household, education, food, health care needs are addressed”(Community Development Officer 1).*

## CHAPTER FIVE

**5.0 DISCUSSION ON THE RELEVANCE AND IMPORTANCE OF THE RESEARCH TO FURTHER STUDY AND ADOLESCENT YOUNG CARERS RESEARCH**

There are several issues raised during the study for further discussion but for the sake of this paper only three most commonly referred issues will be discussed in this section.

The study findings demonstrate the relationship between the tasks performed by adolescent young carers from the perspectives of rights. During the research, participants shared that AYC's are children first and therefore responding to their needs should be prioritized at all times by people in authority. The United Nations Convention on the Rights of the Child (United Nations Convention on the Rights of the Child, 1989) provides a benchmark upon which children should be supported to realise their fundamental rights. In reference to article 1, it clearly defines a child as anybody below the age of 18 years. If that is the case then adolescent young carers taking up parental or caring roles conflicts with the fundamental rights and freedom of young people for equal treatment of all children as universal. One of the key debates around young carers is that it may not be completely eliminated (Nap et al, 2020) but how can the impact be reduced on the adolescent young carers so that they are able to live their lives with optimism and supported achieve their goals in life? This poses a dilemma for social workers who are at the forefront trying to support them to perform their roles and at the same time uphold their rights. How can social workers balance these issues over their universal rights?

Throughout the study social workers and social service workers recognised the fact that these adolescent young carers are children in the first place who have the same rights just like every other child in the world and therefore there should be ways to support them to realise their goals in life and enjoy their childhood. In Uganda the constitution of the republic of Uganda talks about the universal rights of the child, the children's act chapter 59 details the rights of the child and what duty bearers must do to ensure that those rights becomes a reality to every child. It is clear that having the legal frameworks in place is one thing but the implementation of the laws is what

challenges the realization of rights. Whenever social workers are confronted with the issue of young carers it is important that they place their rights first as guided by the social work mandates and principles (International Federation of Social Workers, 2018, Palattiyil et al, 2018). But where there are conflicts with the law should be handled from the perspective of relative pluralism (Healy 2008) And for that to be realised there should be coordination among the different stakeholders to identify and make visible the plight of these category of children so that they are supported to enjoy their fundamental rights and at the same time achieve their dreams in life.

To address the challenges of confinements due to the pandemic, the study participants acknowledged the great contributions played by the informal and the formal Community Support Structures (CSS). These structures are commonly used in Uganda to help in identification and referral of cases at community level (Government of Uganda, 2020). Those mentioned by the interviewees included the child protection committees, parasocial workers, parish chiefs, village health teams, and the local councils. According to the respondents their main roles are to provide first level of support to the community specifically identification of cases, support and referral of cases to stakeholders who could be of support to them. The argument for it is that the community support structures like the child protection communities, parasocial workers, village health teams and parish chiefs have a wealth of knowledge about their communities where they live and they are easier to access in such a time as during COVID-19 pandemic. Such support systems builds on indigenous knowledge that enhances sustainability especially with the limited staff and resources available. This is also built on the existing context where needs addressed are based on the indigenous knowledge of the people. The definition of social work recognizes the importance of indigenous knowledge (IFSW, 2014) in social work practice and encourages social workers across the globe to acknowledge and promote such knowledge the sustainability effect. As a recommendation, the capacities of such structures should be built further to enable them perform their roles better especially during emergency response such as during covid-19 pandemic while integrating the key social work principles. Such a finding is also confirmatory to the social workers and other services providers that communities are not just passive receivers of services but they do contribute a great deal in the planning and execution of

interventions (Adams, 2008). Working with them promotes the principle of empowerment which is core in social work (IFSW, 2018) .

Further findings from the study shows some of the ethical issues that concerns social work interventions with marginalised people. Those that stood out were confidentiality, privacy and the do no harm. This became of concern since the approach and tools for responding to the psychosocial needs of the adolescent young carers changed from mostly face to face interactions to “telecounseling”. While casework was being done through the telephone, the ethics of confidentiality became more pronounced as most of the young carers had no access to phones and so each time they needed to communicate to the social work it would be through the CSS member and in their presence and in such circumstances confidentiality and privacy was hardly observed. Furthermore, how would one express empathy on phone, how would they observe the non-verbal gestures? From the perspectives of the respondents, through “telecounseling” they were in position to offer emergency support to the AYC but how do social workers deal with such ethical issues? According to IFSW (2014), social workers must work with respect and in accordance to confidentiality and privacy of the service users and that indicates that in such a setting there is need for the social workers to devise appropriate measures to ensure that such ethical standards are observed. In the same document, the federation highlights the ethical use of technology and social media detailing that social workers roles in obtaining informed consent to safeguard both the user and the social worker. The researcher suggests the need to strengthen the capacities of social workers towards the digital divide so that services do not lag behind and social workers more accountable to the proof for ethical practice irrespective of the mode of practice (IFSW, 2018). Tough questions to ponder upon is how to balance the technological advancement with social work principles and the values. A practice research of integration of technology into social work case management during pandemics would be importance.

## CHAPTER FIVE

## IMPLICATIONS AND RECOMMENDATIONS FOR SOCIAL WORK PRACTICE

**Recommendations to Social Work Practitioners**

**Re-evaluate the use of tele counselling:** during the study, the social workers needed to find ways of still reaching out to the adolescent young carers and the use of telephones was widely used. The only dilemma was that some of the service users could not afford the phones or could afford data but also there were limitations with network connectivity. But overall, the world is moving towards this direction therefore as a recommendation social workers need to embrace technology in their work and be supported to utilise them effectively. This requires a level of preparation so that during emergencies it can be easily applied.

**Social workers as positive disruptors and can trigger change for the most marginalised.** the study is suggestive that the conditions of young carers are almost taken for granted since it is embedded in the cultures are practices however there are issues of human rights that needs to be delt with. Social workers to get off the rader of normalisation because normalisation is an enemy to the principles of social work and work with relevant structures to challenge the status quo.

**Context matters. Social workers need preparation to adopt models during crisis:** during covid19 pandemic the sudden shift in focus to essential services left a huge gap in service delivery and approaches used. The whole family approach to case management was challenged during the pandemic and therefore was considered less effective in addressing the needs of the AYCs. Even though aspects of it worked, inability to meet together with the family hindered the process.

**Recommendation to Probation and Welfare Office**

The social services department especially the office of probation is well placed in relation to policies and procedures. Through their mandates and position, they can play a key role in leading advocacy initiatives to first of all create more awareness about adolescent young carers and advocate for services that would attempt to address their specific needs especially during crisis such as covid19 times. Already the experience from the pandemic shows that psychosocial needs are important

during emergencies therefore for future pandemics should consider it as one of the essential services Advocate for social services to be prioritised at the onset of pandemics. In the same manner they can push forward legal frameworks that protects adolescent young carers

**Recommendations to the National Association of Social Workers in Uganda:**

There is need for push for user voices to be included in policy decisions in Uganda since it is not adequate

**CHAPTER SIX****CONCLUSIONS**

The research showed the psychosocial needs of adolescent young carers and the whole family approach model during COVID-19 pandemic. In the first place, the study provided a detailed understanding of the psychosocial needs of adolescent young carers during covid-19 pandemic which comprised of psychological and social needs but there was a strong connection with the material needs of the young carers. If such needs are being addressed recommendations were for a holistic approach because failure to meet one need affects the fulfilment of another. Secondly, the study displayed the usefulness of using the community based structures during emergencies like the covid 19 pandemic. It was noted that because of the nature of the disease movements were prohibited to help reduce the spread of the virus and during such a time only the structures on ground could fairly access the adolescent young carers. In addition, the issue of the media was greatly increased during the pandemic which also made the participants to highlight some of the ethical dilemmas such as confidentiality and privacy while using technology in case management.

Overall the study is suggestive that the whole family approach model was not fully relevant in responding to psychosocial needs of adolescent young carers during the covid 19 pandemic and suggests adaptation of approaches based on the nature of the pandemic and the context.



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**ANNEX**  
**CASE STUDY GUIDE**

**Consent**

Dear participant, my name is Miriam Magdalen Alum, an Erasmus Mundus MA Advanced Development in Social work student, conducting a research on the psychosocial needs of adolescent young carers and the whole family approach model relevance in the times of covid19 pandemic as part of the requirement for the award of the master's degree programme. You have been chosen to take part in this study based on your experience as a social worker who supports children and adolescents with child protection and psychosocial support services in Lira district.

Please NOTE that your participation in this study is voluntary and therefore you can withdraw your consent at any point during the study if you are unable to continue. All the information you give, will be kept CONFIDENTIAL only for the purposes of the study.

*Are you willing to participate in the study?*     No     Yes

Name of the organisation.....Title.....



## Description of a Case Study

Based on your practice, produce a case study on an adolescent young carer whom you have supported or interacted with as a social worker. The case study should highlight the circumstances that led to the adolescent young carer taking on a caring role, what their daily routines are, the challenges he or she faces in providing care and how he/she has been coping with the caring role during COVID-19 pandemic. Below are some of the possible guiding questions.

- How do adolescent young carers understand COVID-19 pandemic? Did their caring role change during COVID-19 pandemic? If yes, how?
- During adolescent period, young people experience significant changes, how have these changes been impacted by covid-19 pandemic?
- What psychosocial support services have adolescent young carers received during the pandemic? How different was it from the support they received before COVID-19 pandemic?
- How was the psychosocial support services provided to them? Was it provided to them as a family or individuals?
- How do they feel about the whole-family approach model in addressing their psychosocial needs?
- Any other relevant information for the study.

**ENDS**

## KEY INFORMANT INTERVIEW

### Consent form

Dear participant, my name is **Miriam Magdalen Alum**, an Erasmus Mundus MA Advanced Development in Social work student, conducting a research on the **psychosocial needs of adolescent young carers and the whole family approach model relevance in the times of covid19 pandemic** as part of the requirement for the award of the master's degree programme. You have been chosen to take part in this study based on your experience in working with and supporting vulnerable children and adolescents with child protection and psychosocial support services in Lira district.

Please **NOTE** that your participation in this study is voluntary and therefore you can withdraw your consent at any point during the research if you are unable to continue. During the interview process, the interviewer will take some notes and record the interview proceedings for the purposes of transcription and ensuring accuracy in the data collected. All the information you give, will be kept as **anonymous**, and used only for the purposes of the research.

*I agree*

**Participant name and signature** \_\_\_\_\_

Name of the organisation.....Title.....

**Contact details (email address and telephone)**

Telephone:.....Email address.....

**Researchers details (on behalf of Warsaw University)**

Name and signature \_\_\_\_\_

**Contact details (email address and telephone)**Telephone: +256 778171142      Email address: [miriam.alum@gmail.com](mailto:miriam.alum@gmail.com)

Note: ***If you have further questions about the research, please contact the research team members through the email address provided [miriam.alum@gmail.com](mailto:miriam.alum@gmail.com) or her supervisor Professor Agnieszka Naumiuk, email: [agnieszka.naumiuk@uw.edu.pl](mailto:agnieszka.naumiuk@uw.edu.pl)***

**SEMI-STRUCTURED INTEVIEW GUIDE FOR SOCIAL WORKERS**

Interviewer: Miriam Magdalen Alum

Respondent: .....

**Key questions**

1. Would you please tell me briefly about yourself and your role in TPO Uganda?
2. What do you know about adolescent young carers in Lira? How are they identified and supported?
3. What are your views about the psychosocial needs of adolescent young carers in Lira?
4. How are the needs of adolescent young carers affected by their caring roles?
5. How has these needs been affected by covid19 pandemic?
6. What is your understanding of the whole family approach model?
7. How relevant is the WFA model in responding to the changing psychosocial needs of adolescent young carers during COVID-19 pandemic?
8. What alternative approaches do you as social workers use when responding to the psychosocial needs of AYC?

9. What would you consider as potential factors affecting the use of whole family approach model in responding to the changing psychosocial needs of AYC during COVID-19 pandemic?
10. As a social worker, explain how you addressed the barriers of using a whole family approach model in supporting AYC during COVID-19 pandemic?
11. How do you feel about the support you offered to adolescent young carers through your programmes during COVID-19 pandemic?
12. How do the adolescent young carers respond to the support they received?

Please provide any other relevant information for the study?

**ENDS**

## **SEMI-STRUCTURED INTERVIEW GUIDE FOR SOCIAL SERVICE WORKERS**

Interviewer: Miriam Magdalen Alum

Respondent: .....

### Key questions

1. Would you please tell me briefly about yourself and your role in Lira District Local Government?
2. What do you know about adolescent young carers in Lira District? How are they identified and supported?
3. What policies are in place to respond to the challenges faced by adolescent young carers in Lira district?
4. What are the psychosocial needs of adolescent young carers in Lira? How are such needs affected by their caring roles? How has these needs been affected by covid19 pandemic?
5. What are the existing practices that enhances response to the changing psychosocial needs of adolescent young carers in Lira district?
6. What is your understanding of the whole family approach model?

7. How relevant is the WFA model in responding to the changing psychosocial needs of adolescent young carers during COVID-19 pandemic?
8. What are the barriers in using the whole family approach model in responding to the changing psychosocial needs of AYC during COVID-19 pandemic?
9. Please explain how you addressed such barriers encountered in using the whole family approach model during COVID-19 pandemic?
10. Is there anything you would like to do differently to support adolescent young carers address their psychosocial needs?
11. Please provide any other relevant information for the study?

**Ends**

## **Introductory letter to the organisations**



Miriam's\_Letter to  
Organisations.pdf