CARING FOR HIV POSITIVE CHILDREN: PSYCHOLOGICAL FUNCTIONING OF CARE-GIVERS WITH HIV POSITIVE CHILDREN: A QUALITATIVE STUDY

TIKUR ANBESSA SPECIALIZED HOSPITAL, ADDIS ABABA, ETHIOPIA

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Abstract

Background: HIV/AIDS is an epidemic infectious illness which affects anyone regardless of age, sex, social class, academic level and race. It has a significant direct or indirect impact not only on the patient but also on the care-givers with significant morbidity, mortality and economic burden. Despite an increased care for the infected individual, the psychological impact of the illness on the care-givers has been undermined specially in low to middle income countries including Ethiopia. To date there have been no studies about the psychological functioning of care-givers raising HIV positive children.

Objective: The objective of this study is to explore the psychological functioning of care-givers of HIV positive children following at Tikur Anbessa Specialized Hospital.

Methods: Data was gathered on 14 participants, biological parent and close relative, using semi-structured interviews. The interviews were conducted in Amharic, transcribed and then translated into English. The data were analyzed using thematic analysis

Result; This finding showed that the care-givers age range from 22-85 and 13 out 14 care-givers were female. Majority of them were at low academic level, low socioeconomic status and have temporary employment. Most of them were biological and single parent and they were also sero-positive. The result identified that caregivers experienced emotional pain after hearing the result, persistent or transient maternal guilty, depression, dealing with sero-discordance, discrimination, disclosure concern and change of behaviors in the child. The finding also highlighted the presence of economical struggle, house problem and unemployment on the care-givers. To get through their psychological distress care-givers also used spirituality, hope, getting financial or material support and sharing responsibility with older children as their coping mechanisms.

Conclusion; Caring for HIV positive children is found to be psychologically burdensome especially in a resource limited setting. So, having an integrated mental health service for care-givers is unquestionable. Considering the high burden of care-giving in women, it will be very important to involve male care-givers and empower women economically.

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Abbreviation

AAU—Addis Ababa University

AIDS—Acquired Immune Deficiency Syndrome

ART—Antiretroviral Therapy

DRPC—Department Research and Publication Committee

GHQ-12—General Health Questioner-12

HIV—Human Immunodeficiency Virus

HMIS—Health Management Information System

PI—Principal Investigator

TASH—Tikur Anbessa Specialized Hospital

UNAIDS—Joint United Nations Program on HIV/AIDS

USAID—U.S. Agency for International Development

WHO—World Health organization

Introduction

In 2016, according to Joint United Nations Program on HIV/AIDS (UNAIDS) report 36.7 million people are living with Human Immunodeficiency Virus (HIV) globally among which 15.8 million live in Africa mainly in sub-Saharan African countries. With the same report children and adolescents account 2.1 million each globally. In Ethiopia in the same year there were 718, 500 people who live with HIV among which 65, 088 were children from 0-14 years of age. In 2017, UNAIDS reported that among 127,619 HIV positive people, who were living in Addis Ababa, 2,421 were children under the age of 15.

Although the prenatal treatment of HIV positive mothers with Antiretroviral Therapy (ART) decreased the transmission rate to < 2%, the number of children living with the virus is still high. On the other hand the introduction of ART prolonged the life of the children living with the virus by reducing their mortality rate, which in turn increased the period of care-giving [1]. In Ethiopia since the introduction of free ART, HIV positive children have been having easy access to the medication without any cost. Despite the medical management of the child, the mental health aspects of the illness in on the care-givers are not yet addressed.

The impact of the HIV/ AIDS is multi-dimensional. Besides the health impact it also affects the socio-economical and psychological aspects of the individual and of the care-givers [2-4]. The care-givers who are sero-reactive themselves might have a risk for mental illness on top of which they also struggle in raising their HIV positive children who have different mental health problems such as neuro-developmental disorders, different types of psychiatric illness, unspecified behavioral change and neuro-cognitive disorder [5-6].

Care-givers with HIV positive children can experiences starting from normal stress level up to severe psychological problem to extent of fulfilling criteria for mental disorders [5, 7]. The stigma and discrimination, social withdrawal, fear of disclosure, depression, anxieties, aggression and other mental health disorders are the common psychological impacts faced by care-givers [5, 7-9].

Care-givers psychological distress found to have psychological impact in HIV positive children and this in return causes additional stress on the care-givers [8, 9]. The degree and the types of these psychological distresses also vary based on different factors such as the relationship of the child with the caregiver, severity of the illness and length of diagnosis, presence of an adult with HIV in the house, housing condition, coping ability, availability of social support, socioeconomic status and academic level [7-12].

Care- givers use different types of coping mechanisms to deal with their psychological distress and other areas of burden. Spirituality, wishful thinking, problem-oriented active approach, resource management and sharing responsibilities are some of the adaptive coping mechanisms. Some care-givers also use maladaptive type of coping such as denial, blaming, social withdrawal and avoidance [2, 13]. Psychological distress and other burdens on the care-giver may also sometimes lead to a better coping ability or increased social cohesiveness [14].

There are few studies done in USA, China, Thailand, Haiti, South Africa, Nigeria and Rwanda. These studies showed that care-givers with HIV positive children experience different level of psychological distress and coping strategies. Nowadays there is increased interest towards care-givers than before. This is because of the link between care-givers burden and other treatment related issues such as adherence to the medication, the child's quality of life and psychological distress. To date, there are studies addressing this issue both in low and high income countries.

In a qualitative study done in USA issue of disclosure was the burden for care-givers in relation to stigma and maternal guilt and fear of child's psychological reaction, even if there is increased benefit of disclosing the status [15]. In a study done in China depression is found to be high in care-givers with HIV children. Low education level, low socioeconomic status, lack of household asset and presence of adult with HIV in the house are the factors with elevated risk for depressive symptoms [11].

In another study done in India half of the caregivers with HIV positive children had high score on General Health Questionnaire-12 (GHQ-12) for psychological distress. Being a biological parent, fear of disclosure, stigma and discrimination and sending the child to school were the major factors negatively associated with psychological distress [7].

In a qualitative study done in Thailand the care-givers faced different types of emotional distresses such as fear of losing the child, fear of disclosure, fear of leaving the child due to death in elderly care-givers, dealing with the behavioral change of the child and social stigma and discrimination [16].

In a quantitative study done in Haiti to assess the psychological functioning of the child and their care-givers showed the presence of depressive symptoms in different proportion. These symptoms were sadness, low energy, worthlessness, feeling lonely, hopelessness and suicidal ideation. This study also showed the impact of care-givers depression on the psychological functioning of their children [8].

In a study done in South Africa showed that care-givers experiences depression based on different factors. Some of the factors that are related to depression are caring for AIDS-orphaned children, being female, having low income and housing condition [17]. Care-givers stress is also said to decrease over time as time pass and this depends on the academic level, type of housing and the number of adult in the house [10]

In a quantitative study done in Nigeria about the psychosocial functioning of care-givers with HIV positive people in general 34.8 % of them had no any psychopathology. The remaining showed variable level of stress and depression to the extent of suicide [18]. The impact of care-givers mental illness on the well-being HIV positive children were observed in a qualitative study done in Uganda. Depressed care-givers found to show shouting, aggression and withdrawal from their children [9].

A cross-sectional study done in Hawassa University Teaching Hospital showed that caretakers had the difficulty of disclosing sero-status to their children for different reasons such as fear that it may hurt children' feeling, they might kill themselves, they might not bear the information and they might refuse taking the ART [19]. This study only limited to one of the care-givers' concern on the course of care-giving

In Ethiopia there was a qualitative study done about the pathway and motivation in raising relative's children orphaned by HIV/AIDS. Living arrangements, blood relationship, absence of families and previous relationships are the main pathways to take care of the orphaned children. Their main motivations were lack of choice, caring as a chance of rearing children and spiritual reasons [20]. This study is also limited to the way care-givers end up in the care-giving responsibility.

Few studies tried to show the different type of coping mechanisms that a care-giver do to minimize the psychological and other impacts they face while caring for HIV positive children. In one study done in USA, care-givers tried to cope up with different strategies. These were strengthening the family cohesion, developing positive outlook for life, being interacting with people outside the family, maintaining self-worth, stress management and taking time for oneself [14]. Being informed about the illness, talking to people and being in a self-help group were also the coping mechanisms [14] Another study showed how Care-givers can cope a stress by actively dealing with it or by regulating once own emotion or distracting oneself from the stress [21]. In a study done in Uganda care-givers tried to deal with their difficulties by sharing burden, managing resources and broadening social network [13].

Being a parent is a challenging experience that requires a lot of resources and strength especially in a resource limited country like Ethiopia. On top of this, taking a responsibility of caring for HIV positive children can be demanding not only socioeconomically, but also psychologically. Due to limited evidence about the mental health need of these care-givers, there has been no integrated clinical practice on the matter in our setting. In Ethiopia, although family centered approach in the treatment HIV positive children has been accepted as one component of Guidelines for Pediatric HIV/AIDS Care and Treatment 2014, the routine clinical practice usually doesn't consider the care-givers more than just an accompany to the child on the way to the hospital [23]. Understanding the lived experience of the care-givers from their own perspective will bring an insight to the mental health needs of the care-givers.

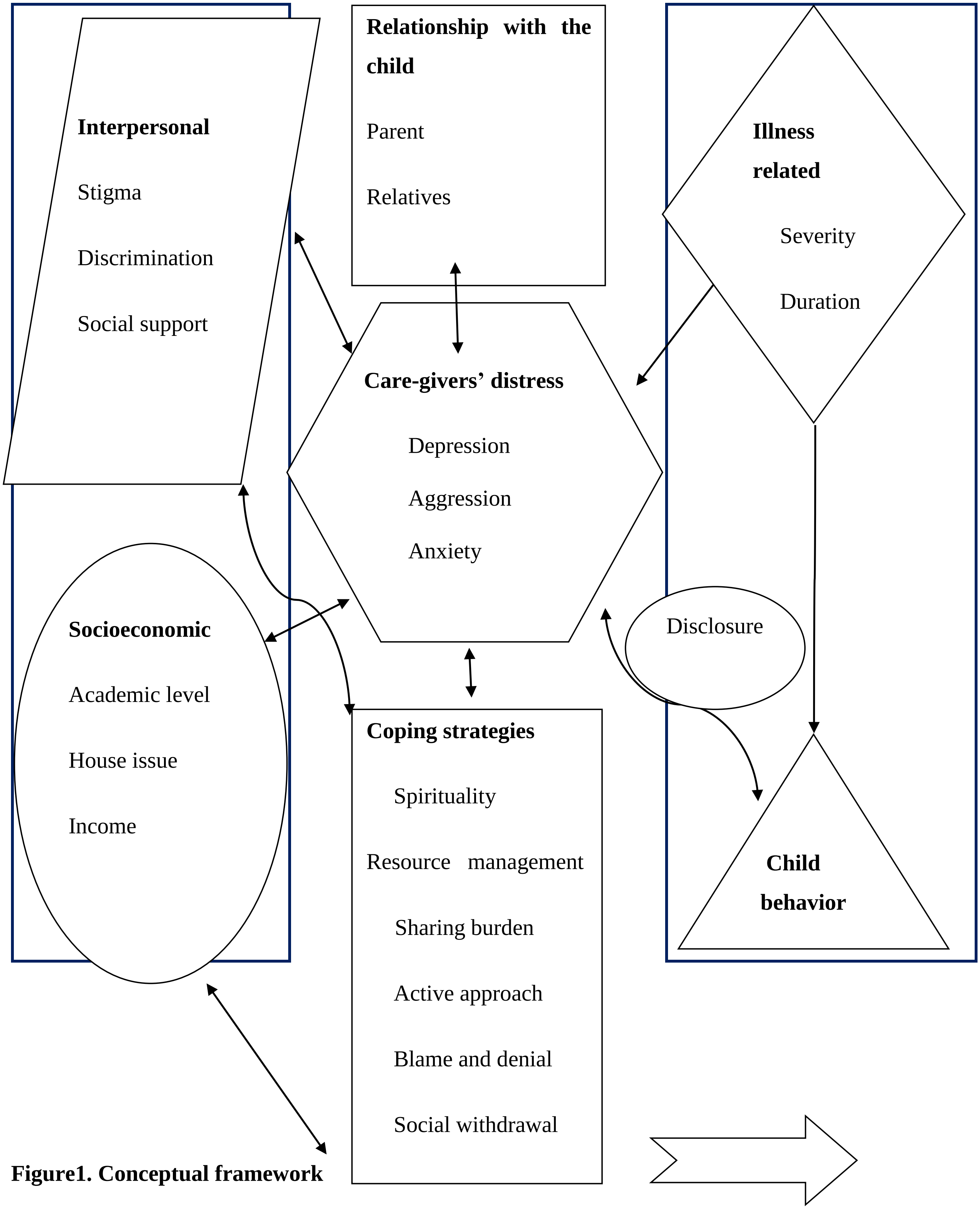

Figure1. Conceptual framework

Significance of the study

In Ethiopia, there have been no studies addressing this matter despite of its common occurrence in clinical practice. The service is usually limited to the child and involves the care-givers as a medium for the communication of the health professionals with the child. Thus this study aimed at exploring the psychological functioning of care-givers with HIV positive children. The result of this study also may have added benefit in improving the routine clinical practice and help care-givers to have an integrated mental health service in TASH, Addis Ababa, Ethiopia.

Research question

What are the psychological distresses experienced by the care-givers?

How other social phenomena are related to the psychological distress?

What are the impact of the psychological distress on the care-givers' social life?

How are the care-givers coping through difficulties in time of the psychosocial distress?

Objectives

General objective

The objective this study is to explore the psychological functioning of care-givers with HIV positive children at TASH.

Specific objectives

- To explore the psychological distress faced by the care-givers with HIV positive children.
- To explore related lived experiences that contributes to the psychological distress.
- To look at the coping strategies of care-givers in giving care for HIV positive children.

Research Methods

Study Design

The study used a qualitative exploratory approach based on semi structured in-depth interviews. This approach was chosen to understand and describe subjective experience and help in gaining insights into care-givers' experiences.

Study Setting

The study was conducted in TASH, which is located in the capital city, Addis Ababa, from April to November 2018. It is one of the largest teaching hospitals in the country under College of Health Science, Addis Ababa University, Addis Ababa, Ethiopia. Pediatric and Child Health department is among the major specialty at this hospital which gives pediatric ART services as part of the program.

The pediatric ART clinic gives service for HIV positive children under the age of 18years. During the time of the study the clinic had six nurses, one resident who stay only for one month and one general practitioner. There was also one consultant who was available in time of consultation. Additionally there were one psychiatry resident, one clinical psychologist and one consultant psychiatrist who were giving psychiatric service for the children once per week. The clinic was giving service on week days starting from 8:30.a.m to 5:00.p.m. On weekends the clinic were also giving service from 8:30am-12:00.p.m. which was also including peer to peer discussion among HIV positive children with the help of a nurse facilitators. There were an average of 15 client visiting the clinic on each day most of which come during the morning hour. The clinic had one office, two outpatients' clinic, one Adherence clinic and one nurse's room.

Participant and sampling procedure

Fourteen participants were recruited with purposive convenience sampling. The numbers of the participant were determined by theoretical saturation. The participants were selected based the predetermined criteria.

Inclusion criteria

- ✓ Care-givers with HIV-positive children <18 years of age.
- ✓ Care-givers who can understand the language of the interview which is Amharic.
- ✓ Care-givers who can give consent for the interview

Exclusion criteria

- ✓ Care takers who doesn’t speak the language of the interview
- ✓ Caretakers with children above 18 years of age
- ✓ Care takers who has speaking or hearing difficulties

Data collection and analysis

In semi-structured interviews, questions that guided the interview were developed. These topic guides incorporated multiple questions that helped open and more flexible descriptions. Amharic was used for gathering of information and the interview with each participant was audio- recorded with the consent of participants. The researcher tried to build good rapport through active listening and empathy to make parents feel understood and helped since the nature of the inquiry might have been distressing for participants. Then the PI transcribed the interview data into Amharic and then translated the interview data and the field note into English.

Before the analysis repeated reading of the transcript and the field note was taken. A qualitative thematic analysis was done with the help of Open Code software version 4.02. Thematic analysis is a method for identifying, analyzing and reporting themes (patterns) within the data (Virginia Braun & Victoria Clarke, 2008). The main topics covered by the interview guide were the starting point and were included as themes at the beginning of the process of analysis. The coding frame was then elaborated and modified as new themes emerged in the course of the analysis.

Ethical considerations

This study was conducted after ethical clearance is obtained from the Department of Psychiatry, School of Medicine; Addis Ababa University. An official letter from the department was submitted to Department Research and Publication Committee(DRPC) and an ethical clearance was obtained from the Department of Pediatrics and Child Health, School of Medicine; Addis Ababa University.

A written informed consent was obtained from all informants who participated in the study after explaining the purpose of the study in the Amharic. Participation in the study was voluntary and privacy of individuals and confidentiality of the information was assured both during and after data collection. All of the participants were informed about their right to resign from being part of the study without any negative consequence on their service at this hospital.

Result

In this study 14 people participated on a face to face in depth interview. The mean age of the participants was 47.2 and majorities of them were females. Nine of them were biological parents, 4 of them were grandparents and one of them was an uncle. Six of them were unemployed and 8 of them were employed or self-employed. Six of them don't have any formal class and the remaining have an academy level starting from primary up to higher class. Five of the care-givers were negative in their sero-status.

Table1. Demographic characteristics of care-givers

Respondents	Age	Sex	Marital status	Employment	Education	Sero-status	Relationship with the child
01	55	M	Married	Self-employed	No formal education	Negative	Uncle
02	63	F	Widowed	Unemployed	Secondary	Negative	Grandmother
03	75	F	Widowed	Unemployed	No formal education	Negative	Grandmother
04	42	F	Widowed	Employed	No formal education	Positive	Mother
05	38	F	Divorced	Unemployed	Secondary	Positive	Mother
06	22	F	Divorced	Self-employed	Primary	Positive	Mother
07	43	F	Widowed	Employed	Primary	Positive	Mother
08	85	F	Divorced	Employed	No formal education	Negative	Grandmother
09	23	F	Widowed	Self-employed	No formal education	Positive	Mother
10	30	F	Married	Self-employed	Higher	Positive	Mother
11	45	F	Married	Unemployed	Primary	Positive	Mother
12	40	F	Married	Self-employed	Primary	Positive	Mother
13	78	F	Divorced	Unemployed	No formal education	Negative	Mother
14	30	F	Married	Unemployed	Primary	Positive	Mother

Six care-givers get their child tested at the time of birth and eight of them got their child tested in the age range of 2-15. All of the care-givers are sending all school age children to school. Nine of the care-givers disclosed the child's status to the child, but the remaining five care-givers didn't. Those children who are disclosed have the age range of 7- 12 year and those aren't disclosed has the age range of 2-15 year. All of the care givers got their children started on ART immediately after the result except one of them.

Table2. Demographic characteristics of the child

SN	Characteristics of the child		Frequency
1	Age	0-5	1
		6-10	3
		> 11	10
2	Sex	Female	5
		Male	9
3	Education	No formal education	1
		Primary	13
		Secondary	0
		Higher	0
4	Illness duration	0-5	8
		6-10	5
		> 11	1
5	On ART	Yes	14
		No	0
6	Duration on ART	0-5	8
		6-10	5
		> 11	1
7	Disclosure	Yes	9
		No	5

As part of the analysis two themes were identified; 1. Emotional and behavioral experience 2. Coping strategies and six categories were identified; way to screening, course on the care-giving, interpersonal, disclosure concern, non-instrumental and instrumental coping strategies

Emotional and behavioral experience

Way to screening

Care-givers got their child tested due to different reason such as knowing once own sero-status and incidental screening due to other medical condition. All of the care givers got their child tested immediately at the time of their suspicion or after health care provider advice.

Few of the care-givers were expecting their child to be positive. This expectation was independent of care-givers sero-status and relationship with the child. Most of the care givers specifically the biological parents reacted to the result with shock, sadness, hopelessness, tearfulness and denial of the result; "*To tell the truth, I didn't cry when I heard my result, but on the day I heard his result, I cried so hard because it was difficult" [Respondent 12].*

But more than two third of the care-givers accepted the result immediately, except one of them saying; "*I still don't accept the result" [Respondent 10]*, even if it has been more than 10 years since she knew the result. Most of the care-givers were curious how, when, where and why this happened and had the explanatory model that the illness happened because of God's will or punishment; "*what is happening is nothing but what God has brought it" [Respondent 13]*

Course in the care-giving

All the care-givers suffered an immediate fear of losing their child with death and they were not seeing any hope about that. All of the biological parent were suffered a transient or persistent self-blame or maternal guilty about transmitting the virus to their child; *"I feel guilty, if I had known earlier her life would have been different but it's difficult to explain" [Respondent 10]*.

For most of these care-givers the self-blame was transient just during the time they heard the result, but few of them faced intermittent self-blame whenever they encounter a painful reminder;

"when the kid ask me few some question or when I see his physical and compared him with his peer there is reduction somehow….I am the one who knows his face…..I am the one who knows his inside…..when I see him in between children I feel sad from inside…but I can't do anything other than being sad" [Respondent12]

Around half of the care-givers reported that they have been experience change of mood and behavior for months to years after they heard the result of their child. Most of these changes were constant irritability, guilty, hopelessness, inability to be happy, tearfulness and unexplained emotional pain, low energy, worries, suicidal ideation, poor sleep, poor appetite, and mild occupational impairment. Most of these care-givers had spontaneous recovery, but few of them still have isolated or few group of symptoms.

"*Starting from the beginning I have low energy …I had poor appetite…….you know, you convince yourself that what if I don't live…..I have been irritable and lack patience. I usually not able to let go of things when someone say something and talk with powerful words…..it has been long since I planned something……simply I am living fake life since i knew the result" [Respondent 12]*.

Having burn out, fear of pregnancy, uncertainty about the future and helplessness is some of the emotional experience reported by few respondents. Low income, house or housing problem, being a biological parent, sero-discordance, being a single parent were some of the factors related to care-givers' distress.

Interpersonal

Three of the biological parents were sero-discordant and in this relationship two of the women were the one who were sero-reactive. Only one of the care-givers said she doesn't have any problem in her marriage despite her husband being negative for HIV. All of them didn't get divorced, but stayed in a disharmonious marriage which includes not talking to each other, not financial support each other or exchanging powerful words;

"*He is my first husband. I didn't marry anyone else….after I immediately got my result, I just told him to get tested….he told me why I am making a big deal out of it…..he said everybody is dying including the rich not only me…..he didn't give a damn when I was worried…..he has been not worried about the kids and I was surprised by that. I decided that he is the one who brought the illness…..we don't have a normal conversation with him for about three or four year….we came and go to the house. To tell you the truth, for such long time he doesn't understand the problem….he doesn't know the illness…he doesn't know what the medication did to me" [Respondent12]*

All of the care-givers reported that they have good relationship with their child both before and after disclosure. "*It is good we care for each other …she don't want to do things without me…she has a good mind which is better than other kids at home" [Respondent02]*. Most of their children have been receptive of the advice given by the care-givers, the explanation given for the question they raised and complaint to taking their medication even before disclosure. Few of them also found to be understanding of the financial burden their care-givers has and tried to engage in child labor; "*We are good. She does what she is told. "We bounce ideas between us. We advise and criticize each other when we have to" [Respondent11]*.

Most of the care-givers were open while interacting with the PI during the interview and they seemed comfortable while talking. Majority of the biological showed sad facial expression and sad tone in their voice while remembering the time screening. Only one of the care-givers was tearful frequently with fragmented speech *[Respondent 4]*. Three of the care-givers were showing different level of anger while talking about their partner *[Respondent06, 12]*. Most of them were having brighter facial expression while talking their current condition.

Disclosure concern

Disclosure was also a concern for most of the care-givers. Before disclosure majority of the care-givers faced a question by their child about the medication most of which gave another medical explanation; "*We usually tell her that there is bacteria in your blood and it will disappear and that will be the time the medication will be stopped "[Respondent 02].* Only two of the child was irritable about taking the medication.

Most of the care-givers gave different explanation about the difficulties in disclosing the child about his/her status. Most of the explanation was fear of the child getting hurt, fear of the child being telling his status to his friend at school and the resulting impact, fear of the child might refuse taking the medication and fear of facing different question from the child. "*If I tell her she might tell her friends at school who will tell their parents like she talks to me. Then they will discriminate her, so I should tell her in a systematic way "[Respondent 10].*

After disclosure only two of the child showed change in behavior to extent of having high risk suicidal attempt "*He doesn't play with kids. He isolate himself.......he has poor academic performance.....He repeated grade eight……. He doesn't talk with his father by mentioning that it makes him upset whenever he see him……He often says his father is the one responsible for our condition and he wants to kick him on the head and go to prison. He also tried to overdose himself with the ART and was having vomiting and treated in a hospital.....he also tried to burn himself by spilling kerosene on himself and set fire, but only his trouser got burned"[Respondent12]*

Most care-givers keep the secret only in the family which includes father or mother, siblings, grandparents and second degree relative and only three of the care-givers disclosed to neighbors. None of them disclosed the child condition to the school. Few of them encountered discrimination from their relatives and neighbors, but most of them have good support; "*they love him as their child…I don't have sisters or brothers, but my neighbors take care of him as mother …he usually spent in their hand…I don't have any bad feeling….thanks to god" [Respondent 03]*

Coping strategies

Non-instrumental

Most of the care- givers used spiritual activities as their coping mechanisms such as praying, reading bible, drinking holly water and applying “KIBA-KIDUS” as one respondent said :“*there is no worries….it happened because of god’s will…it is better to accept it…I usually go to church to pray and take holy water …..I too apply “KIBA-KIDUS” [Respondent06]*. Reliance on religion is also one of the means that helped caregivers to get through their hard time: *“God is my hope, he is the reason for my daughter’s and my survival, and when my time comes, I will go gladly*” *[Respondent11]*.

Few care-givers used chatting with family members, the child himself or herself, friends, with another care-givers during their follow up encounter, crying and going to sleep in time of stress; *“I usually cry and got to sleep and when I wake up I feel better” [Respondent12]*. Most care-givers hold on to their hope and use their determination to get through some of their difficult times; “*it is for good…it is better to get through it that way…if I cried out or think too much of it, it is going to be just tiresome…..so it is better to be brave and take care of the sick one” [Respondent 03]*.

Instrumental

In some circumstance having support from family members includes older children, grandparent and other relatives. The support included mostly instrumental such as financial, household work and taking care of the child on his medication or taking the child for follow up:

“There is my oldest son who support me with money and if I asked him about this kid’s cloth or dressing or medication, he will buy him that. I just give him what the patient want….he is not the same as before, now his sister is the one that support me …even she doesn’t want to me to work on such things such as washing cloths and cleaning the house….she told me to rest [Respondent 07].

Neighbors are also found to be a great support in taking care of the child in the absence of the care-givers; "*when I have funeral and any other problem my neighbor take care of the boy and give him medicine"[Respondent 13]*. Different group of people such as friends, and other group of the society was also the source of support: "*different people extend their hand for help including from this hospital….and when those people who let him attend class give him something I buy things to eat" [Respondent 03]*

Few care-givers used hard work, borrowing money, and sacrifice as their coping mechanisms; *"I got him started on the ART immediately. It was for me that took so long to start the medication. I wasn't concerned about myself, but for him. The doctors advised me to live for my son. I began to understand that I should live for him. My son doesn't have anyone to grow him up if I died, so I started my medication and now everything is okay" [Respondent06]*. Only one care-giver reported the use of a substance at the time of emotional pain.

Discussion

In this study most of the care-givers were expecting negative result regardless of their own sero-status and relationship with the child. Their reaction to the result was also independent of their expectation, but biological parents reacted more than relatives with denial, shock, tearfulness, curiosity and fear of losing their child. All of the care-givers got their children tested immediately after they find the reason. Most of the care-givers had the explanatory model that, the illness happened due to God' will or punishment. There has been no studies regarding the care-givers' experience at the time of screening to compare to this study.

This study also found that around half of the care-givers reported that they have been experience change of mood and behavior for months to years after they heard the result of their child. Most of these changes were constant irritability, maternal guilty, hopelessness, inability to be happy, tearfulness and unexplained emotional pain, low energy, worries, suicidal ideation, poor sleep, poor appetite, and mild occupational impairment. Most of these care-givers had spontaneous recovery and few still have isolated or few group of the above symptoms. In a study done by Mary et al. there was similar finding showing that care-givers were experiencing different level of depressive symptoms such as sadness, loneliness, energy, worthlessness, feeling lonely, hopelessness and suicidal ideation [8]. But the study showed that care-givers with depression reported more psychological symptoms on their children than non- depressed which is not the case in this study except on one of the respondent.

In this study being a biological parent, low income, house problem and discordance were some of the factors that were related to more psychological distress in care-givers. In a similar study done in China depression is found to be high in care-givers with HIV positive children. Low education level, low socioeconomic status, lack of household asset and presence of adult with HIV in the house are the factors with elevated risk for depressive symptoms [11]. Similar studies done by Caroline et al. also showed that similar factors were associated with care-givers' depression [17].

In a study done by Hailemariam et al, on the sexual life and the fertility desire in sero-discordant couple showed that HIV sero-status had effect on the desire to have children. Shifting of the interest, living with the discordance, change in sexual life and the desire to balance safe sex and having a child were some of the challenge in these couples [22]. In this study four of the biological parents were sero-discordant. Even if all tried to maintain their marriage, they all went through different types of difficulties. These include different interest for having a child, strong interest toward divorce by sero-reactive partner, and complete marital disruption to the extent of not sharing anything despite living in the same house.

Care-givers also suffered fear of losing their child, fear of leaving the child behind due to death, discrimination and transient or persistent self-blame for transmitting the virus to their child according to this study. In a qualitative study done in Thailand the care-givers also faced similar types of emotional distresses such as fear of losing the child, fear of disclosure, fear of leaving the child due to death in elderly care-givers, dealing with the behavioral change of the child and social stigma and discrimination[16].

In this study most of the care-givers faced difficulties in disclosing the child about his/her status. Most of the explanation for their fear was fear of the child getting emotionally hurt, fear of the child being telling his status to his friend at school and the resulting impact, fear of the child might refuse taking the medication and fear of facing different question from the child. This finding is similar to the finding from a quantitative study done by Tadesse et al, in Hawassa. The study found that 77.8% of the care-givers believed that disclosure is important, but they experienced fear of disclosure due to different reason such as fear that it may hurt children' feeling, they might kill themselves, they might not bear the information and they might refuse taking the ART [20].

In our study almost all of the care-givers faced different question by their children about the medication before they were disclosed. Most of our respondent gave answer by telling different medical explanation or telling that it is a "life sustaining" medication. But in another study, only less than half of the children asked question about the medication before disclosure. These care-givers used different answer such as telling lies, deflecting the information and disclosing the HIV status [20].

In this study 2 children showed behavioral change after disclosure. They showed irritability, isolation, anger toward family member, suicidal ideation and attempt and low academic performance. In a study done by Jeena et al, similar finding was observed in which only two of the children showed isolation and drop in academic performance after they were disclosed [4].

On other study, schools know the status of 12 children out of 20 where one of them faced discrimination [4]. This contrast with the case in our study which found that none of the care-givers disclosed their child status to school or the schools don't know the status of the child by any means. These can be due to the care-givers need to protect the child from the stigma and discrimination from the school community.

In a study done by Sharon et al**,** care-givers tried to cope up with different strategies. These were strengthening the family cohesion, developing positive outlook for life, being interacting with people outside the family, maintaining self-worth, stress management and taking time for oneself [14]. But in our study the care-givers mostly relied on religion or spirituality, talking to people, crying and sleeping to deal with their stress. Few of them used sharing responsibility, working hard, getting material or financial support from different group of people. This difference can be due to the parent decision to keep the status private.

Trustworthiness

The investigator tried to incorporate participant from different age group, different living circumstance and different relationship with the child to have a variety of rich perspective in the phenomenon. Considering the sensitive nature of the condition a one to one in depth interview was the appropriate way to gather the data. The question from the topic guide tried to includes step by step experiences of care-givers starting from the time of just before screening and the time after wards. The investigator went through multiple coding to have an optimal meaning unit for each code.

The investigator tried to maintain consistency on the focus of the question for each participant while addressing the emergence of new insight at each interview. Consistent data analysis was also followed and a contextual detail description of the themes with quotation was given to make it understandable by readers.

Limitations

This study addressed the concerning mental health issue of care-givers with HIV positive children. Considering the medical nature of the service which is usually limited to the child, the finding of this research will give an insight to have an integrated mental health service to this group of population. It also gives help for large scale research on the area in the future. Despite that this research also has its own limitation. These are small sample size, limited number of male care-givers and didn’t include the children’s perspective. Since a study can only focus on specific questions, there was little opportunity to focus in detail on child behavior and difficulties which could have painted a better picture of the entirety of the experience. These limitations indicate that the experience of parents could be much greater and complex than that stated in the paper. Making triangulation could have resulted good trustworthiness, if it wasn’t due to limited resource and time.

Conclusion and Recommendation

This study highlighted the experience of care-givers experience while caring for HIV positive children. The study identified that the care-givers' psychological distress start even before and at the time screening. Care-givers showed to make quick decision after they found a reason to get their child tested. Despite anticipation of negative result and painful emotional reaction, care-givers were able to overcome that and started taking care of their child.

Care-givers also experienced persistent or situation based isolated self-blame or depressive symptoms. For most care-givers these depressive symptoms or self-blame or behavioral change faded away with time spontaneously. House problem, low income, sero-discordance discrimination and lack of support were the additional factors that caused psychological distress in care-givers.

Care-givers also went through difficult situation about disclosure. Fear of the child being hurt, fear of the child talking to friends, fear of the child refusing medication and fear of blame or facing unanswerable question were the factors that lead care-givers emotional distress.

Care-givers used different coping strategies most of which were being spiritual or reliance on religions. Their explanatory model that the illness happened because of the "will of god" was also one of the way that help care-givers adjust themselves with the condition. In this study care-givers didn't participate in support group, free chat with the close families or friends. Crying or using substance was also some of stress relieving strategies used by care-givers in time of distress. Sharing responsibility, having financial or material support from family members or friends, working hard and having older children at home were the also the coping that care-givers used to deal with their instrumental need.

Most of the findings from this study have similarities with previous studies on the same area despite of socio-demographic difference in between different group of populations. Including psychological support starting from the time of screening and afterwards as an integrated health provision will help care-givers to well adjust to this unchangeable condition. This can be achieved by giving a level based mental health training to the clinic staff by mental health professionals or working toward involving psychiatric unit in the matter.

As per this study women are the one who takes the care-giving burden on top of which low socioeconomic status and low academic level negatively impacted their way of handling the situation in a better way. So, empowering women socioeconomically and academically at national level will help them to cope with the condition. Additionally it also helps them to have better involvement on the prevention of the illness transmission both vertically and horizontally. Encouraging involvement of male care-givers starting from the time of screening and the time afterward will have significant impact on reducing the psychological distress faced by women. Care-givers from this study reported that the counseling they get from the clinic is limited to adherence or medication related issues which usually involve the child. So, addressing the psychosocial aspect of the care-giving or preparing a support group within the care-givers at institution level might help the care-givers to enrich their experience.

In this study two of the children showed change in behavior with high suicidal risk on one of them, so having close follow up after disclosure or carrying out pre-disclosure assessment the child readiness at institution level has paramount importance.

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Appendix

Data collection form

SN	**Care-givers**	
1	Code	
2	Age	
3	Sex	Male
		Female
5	Marital status	Single
		Married
		Divorced
		Widowed
6	Occupation	Employed
		Unemployed
7	Educational status	No formal education
		Primary
		Secondary
		Higher
	Sero-status	Reactive Non-reactive
	Care recipient	
1	Age	
2	sex	Male
		Female
3	Educational level	Not attending
		Primary
		Secondary
		Higher
4	ART	Yes
		No
5	Duration of diagnosis	
	Disclosure	Yes
		No

የመረጃ መሰብሰቢያ ቅፅ

ተ. ቁ	አሳዳጊ	
1	ኮድ	
2	ፆታ	ወንድ ሴት
3	ዕድሜ	
4	ትዳር	ያላገባ ያገባ የተፋታ የሞተበት
5	ስራ	የግል የመንግስት የሌለው
6	ት/ት ደረጃ	ያልተማረ 1ኛ ደረጃ 2ኛ ደረጃ ከፍተኛ
7	HIV ውጤት	ፖዘቲቭ ኔጌቲቭ
	ልጅ	
1	ፆታ	ወንድ ሴት
2	ዕድሜ	
3	ት/ት ደረጃ	ያልተማረ 1ኛ ደረጀ 2ኛ ደረጃ ከፍተኛ
4	ህመሙ ከታወቀ ስንት ጊዜ ሆነው	
5	የፀረ HIV መድሃኒት	ይወስዳል አይወስድም
6	የፀረ HIV ማድሃኒት ከተጀመረ ስንት ጊዜ ሆነው	
7	ስለ በሽታው ተገልጾለታል	ተገልጾለታል አልተገለጸለትም

Topic guide

1. What is your relation with the care recipient?
2. What were your experiences when you first heard about the child sero-status?
3. What is the impact of raising HIV positive child?
    - 3.1. In your interpersonal relationship
    - 3.2. In your personal growth
    - 3.3. On your mental health
4. What are your feelings in raising a child living with HIV with regard to?
    - 4.1. your attitude toward yourself
    - 4.2. your hope about your future
    - 4.3. your sense of purpose
5. What were your worries about disclosing the sero-status of the child to him/her?
6. How is your relationship with your child after disclosure or what do you expect will happen after disclosure?
7. What are your experiences about people attitude toward your child sero-status?
8. What does the future hold for your child?
9. What is your experience about getting counseling from the center?
10. Where do you get support that helps you during difficult times?
11. What kind of strategies do you use whenever you encounter psychosocial difficulties?

የመጠየቂያ ነጥቦች(ቶፒክ ጋይድ)

1. ከታካሚው/ዋ ልጅ ጋር ያለዎት ግንኙነት ምንድነው?
2. ለመጀመሪያ ጊዜ ልጅዎ ሂቨ በደሙ እንዳለ ሲነገርዎት ምን ተሰማዎት ?
3. HIV በደሙ ውስጥ ያለን ልጅ ማሳደግዎ ምን አይነት ችግር ፈጠረብዎት?
    3.1. ከሰዎች ጋር ባልዎት የእርስ በእርስ ግንኙነት ላይ?
    3.2. እራስን ከማሳደግ ጋር ተያይዞ?
    3.3. በአእምሮ ጤንነት ላይ?
4. HIV በደሙ ውስጥ ያለን ልጅ ማሳደግዎ ምን አይነት ስሜት ፈጠረብዎት?
    4.1. ስለራስህ ባለህ አመለካከት ላይ?
    4.2. ስለወደፊት ባለህ ተስፋ ላይ?
    4.3. ስለህይወት ባለህ ትርጉም ላይ?
5. ለልጅዎ HIV በደሙ መኖሩን ለመንገር የሚያስጨንቅዎት ነገር ምን ነበር/ ምን ያስጨንቅዎታል?
6. ለልጅዎ HIV በደሙ እነዳለ ክገለጹለት/ላት በኃላ የእርስ በእርስ ግንኙነታችሁ ምን ይመስላል/ ምን የሚሆን ይመስልዎታል?
7. የሰዎችስ አመለካከት ምን ይመስላል?
8. ስለልጅዎ የወደፊት እጣ ፈንታ ምን ያስባሉ ?
9. የምክር አገልግሎተ የማግኘት ልምድዎት ምን ይመስላል?
10. ፈተናዎች ሲያጋጥሞት ድጋፍ ከየት ያገኛሉ?
11. ማህበራዊና የስነ-ልቦና ችግርዎን ለመፍታት ምን አይነት መፍትሄ ይጠቀማሉ?

Participants' information sheet

I am conducting a research project about psychological functioning of care-givers with HIV positive children. This form will explain why the study will be conducted, the role of yours, the possible benefits of involving in the study and confidentiality of the information you give for the study. There is no expected or perceived harm to you by participating in this study.

This will be done by conducting an interview using questions for each participant. The interview will take up to 60-90 minutes, but the duration and structure will primarily be determined by your (participant's) responses. The questions you will be asked focuses on the psychological distress and your coping mechanisms in raising HIV positive children. With your permission, the interview will be audio-recorded. Your confidentiality will be strictly protected and no names will be recorded throughout the study.

After data is converted into English language, it will be stored in password protected folders. Any personal information that could lead to your identification will never be disclosed in either written or oral form. You have the right of free choice to participate in the study without any obligation. If there is any question that you don't want to answer you can miss out that question. You can ask further clarifications of questions that are not clear to you. Anytime during the interview, you can ask for a break, to reschedule. You have a full right to withdraw from the study or choose not to participate at any time without consequences. This will have no effect on the service you and your child receive from this hospital. I would also like to inform you that this study was approved by the ethical committees of the Department of Psychiatry and department of pediatrics, TASH, AAU

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የተሳታፊዎች መረጃ ቅፅ

ከHIV ጋር የሚኖሩ ህሳናትን የሚያሳድጉ ዐሳዳጊዎች ያለባቸው ጫና እና ጫናን የመቋቋም አቅም የሚል ጥናት እያደረኩ እገኛለሁ፡፡ ይህ ቅፅ ጥናቱ ለምን እንደሚካሄድ ፣ እርሶ ተሳትፎ ምን እንደሚመስል፣ በጥናቱ በመሳተፍዎ የሚገኝ ጥቅም እንዲሁም ሚስጥራዊነትን በተመለከተ ያትታል፡፡ እዚህ ጥናት ላይ በመሳተፍዎ ይደርሳል ተብሎ የሚጠበቅ ወይም የሚደርስ ጉዳት አይኖርም፡፡

ይህ ጥናት ለሁሉም ተሳታፊዎች እንዲሆን ተደርጎ በተዘጋጀ የጥያቄ ነጥቦች ላይ ተመስርቶ ይካሄዳል፡፡ ይህም ጥያቄና መልስ ከ60-90 ደቂቃ የሚወስድ ሲሆን የጊዜው ርዝመትና የጥያቄው ቅርጽ ግን በእርሶ ምላሽ ይወሰናል፡፡ ጥያቄዎቹም HIV በደማቸው ያለን ልጆችን የሚያሳድጉ ሰዎች ያለባቸው የስነ-ልቦና ጫና እና የመቋቋም አቅም ይደስሳሉ፡፡ በእርሶ ፍቃድ ቃለምልልሱ በድምፅ የሚቀዳ ሲሆን ሚስጥራዊነቱም በእያንዳንዱ የጥናቱ ሂደት ላይ የተጠበቀ ይሆናል፡፡ የሚሰበሰበው መረጃ በሚስጥራዊ ቁልፍ ተጠብቆ የሚቀመጥ ይሆናል፡፡ ማንኛውም የእርሶ የሆነ መረጃ በፅሁፍም ይሁን በቃል ለማንም ተላልፎ አይገለፅም፡፡

በጥናቱ ውስጥ ያለማንም አስዳጅነት በእራሶ ነፃ ፈቃድ የሚሳተፉ ሲሆን መመለስ የማይፈልጉት ጥያቄ ካለ አለመመለስ ይችላሉ፡፡ ግልፅ ያልሆነ ጥያቄ ካለ እንዲብራራሎት መጠየቅ ይችላሉ፡፡በቃለ-መጠይቁ መሀል እረፍት ማድረግ ወይም ተለዋጭ ቀጠሮ መያዝ ይችላሉ፡፡ከጥናቱ በማንኛውም ሠዓት አቋርጠው መውጣት የሚችሉ ሲሆን ይህም በእርሶ ላይ የሚያመጣው አንዳችም አሉታዊ ችግር አይኖርም፡፡ ይህ ጥናት በአዲስ አባባ ዩኒቨርሲቲ ጥቁር አንበሳ ሆስፒታል የስነ-አእምሮ እና የህፃናት ህክምና ክፍል ኢትካል ኮሚቴ ፀድቆ የተፈቀደ መሆኑን ለማስገንዘብ እወዳለሁ፡፡

ጥናት አድራጊ፡- ዶ/ር አሸናፊ ነጋሽ፤ የመጨረሻ አመት የስነ-አእምሮ ህክምና ሬዚደንት

ኢሜል፡- letgoket@yahoo.com/ letgoket@gmail.com

Participant consent form

My name is________________________. I have received and understood the information I have been given verbally and in the letter of invitation to take part in the study which composed of an interview that explore about the psychological functioning in raising HIV positive children. I have received adequate information regarding the nature of the study and understood what will be expected from me. I have understood that participating in the study entirely depends on my decision to participate and that I have all the rights to withhold information. I have understood that the confidentiality will be kept for all the information I give during the study and I have also the right to refuse or dropout of the study any time I want to do so without any negative consequences. I also agreed the interview to be audio-recorded and finally I hereby consent to participate in this research study.

Participant's signature:________________________

Date: -----/-------/-------

PI signature:____________________

Date; -----/--------/--------

የተሳታፊ የስምምነት ቅፅ

እኔ ስሜ ---------------------------------- ሲሆን በዚህ ከHIV ጋር የሚኖሩ ህፃናትን የሚያሳድጉ ሰዎች ሊያጋጥማቸው የሚችል የስነ-ልቦና ጫናና ጫናውን የሚቋቋሙበት መንገድ በሚለው ጥናት ላይ እንድሳተፍ በፅሁፍም በቃልም ገለፃ ተደርጎልኝ ተረድቻለሁ፡፡ ስለጥናቱ ምንነትና ከእኔ ምን እንደሚጠበቅ በቂ መረጃ ተሰቶኛል ፡፡ በጥናቱ ላይ ያለማንም አስገዳጅነት የምሳተፍ ሲሆን መናገር የማልፈልገውን ነገር አለመናገር እንደምችል ተረድቻለሁ፡፡የምሰጠው መረጃም ሙሉ በሙሉ ሚስጥራዊነቱ የተጠበቀ መሆኑ ተገልጾልኝ ተረድቻለሁ፡፡ ከጥናቱም በማናቸውም ሠዓት አቋርጬ መውጣት እንደምችልና ይህም ምንም አይነት አሉታዊ ችግር እንደማያስከትል ተገልጾልኝ ተረድቻለሁ፡፡ በተጨማሪም ቃለ መጠየቁ በድምፅ እንዲቀዳ ፈቃደኛ ሆኛለሁ፡፡ይህንንም በመረዳት በዚህ ጥናት ላይ ለመሳተፍ ፍቃዴን ሰጥቻለሁ፡፡

የተሳታፊ ፊርማ፡-----------------------------------

ቀን፡ --------/--------/----------------

የጥናት አድራጊው ፊርማ፡-------------------------

ቀን፡------/--------/----------