

# Adherence To High Active Antiretroviral Therapy (Haart) During Covid-19 Pandemic : Women Caring For An Hiv-Infected Child Coping Experience

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## Abstract

The experience of caring for AIDS orphans raises a wide range of caregiving challenges. It has a significant impact on the entire extended family during the caregiving process. This article represents a report on specific findings from an exploratory study focusing on women living with HIV caring for an HIV-infected children during the COVID-19 pandemic. The major concern of HIV caregiving during the COVID-19 lockdown was the HIV medication and treatment adherence. This qualitative study was designed using a phenomenological approach, with an in-depth interview method used to collect data. The selection of informants was made using purposive sampling. Apart from that, the scope of the interview questions was developed from the literature. Four orphans' AIDS caregivers were interviewed. The results showed all informants had practiced Strength-Based coping mechanisms during the lockdown. This action is a catalyst in maintaining the social well-being of caregivers while being identified as being able to provide new hope for the AIDS orphans under their care. Caregivers are resilient and were adhered to HIV antiretroviral medication routine for children under their care by i) showing acceptance of the Orphans' AIDS seropositive status, ii) well-planned problem-solving and confrontation approach, iii) receiving continuous social support (emotional and instrumental support) and iv) practising cognitive restructuring and developing positive behaviour based on their past experiences related to HIV/AIDS caregiving challenges. The results are expected to bring a positive impact on helping HIV children's caregivers to strengthen the existing coping strategies which were practiced during COVID-19 lockdown period. Additionally, this study foresees a significant contribution to Social Work Practices with families and the needs to develop a home-based AIDS Orphan care module.

**Keywords:** Coping Strategies, Adherence with HIV Medication, caregivers, HIV Children.

## Introduction

*Human Immunodeficiency Virus (HIV)* and *Acquired Immune Deficiency Syndrome (AIDS)* is one of the most serious public health crises in the global health system (Atanuriba et al. 2021; Peltzer et al. 2016). The HIV/AIDS epidemic is wreaking havoc on the socio-economic structure of global development (Kyomuhendo et al. 2021; ICAD, 2006) and threatens the family system of world society (Li et al. 2015; Lata & Verma, 2013; & Rotheram-Borus et al. 2005). According to UNAIDS (2021), the global HIV epidemic recorded the number of HIV-related deaths by the end of 2020 at 680, 000 cases. Malaysia is no exception in recording 2,000 deaths due to AIDS (UNAIDS, 2021). UNAIDS (2021); Mamukeyani (2021); Avert (2020); and Orne-Gliemann et al. (2008), stated that death due to HIV/AIDS among productive age people (15-45 years old) has left many children into orphans' status. This situation has raised various issues related to the acquisition of AIDS orphan care in the community. The role in orphans' AIDS caregiving shifted from formal care to their extended families is often associated with socioeconomic issues, skills, and knowledge among orphans' AIDS caregivers (Maddocks & Chetty, 2020; Ezarina & Haris, 2017; Karimli et al. 2012).

Based on global statistics released by UNICEF (2021) and UNAIDS (2021), an estimated 15.4 million children under the age of 18 have had one or both parents die from HIV/AIDS by the end of 2020. UNAIDS classifies these children as AIDS orphans (Frood & Pursell, 2020; Ezarina et al. 2018; UNICEF 2016; UNAIDS, 2010). The Sub-Saharan Africa population has a great number of AIDS orphan statistics, which covers 11.5 million cases (UNAIDS, 2021 and UNICEF, 2021). Indonesia, Thailand, and Vietnam are the Southeast Asian countries with a high number of AIDS orphans (UNAIDS, 2021). Malaysia is also included in these phenomena. According to the *Global AIDS Monitoring Report 2021 – Malaysia HIV/AIDS Progress Report* until December 2020, Malaysia records 45,000 children aged 0 to 17 as AIDS orphans. AIDS orphans is a general term not only for HIV-positive children who are infected by positive mothers during pregnancy, childbirth, or breastfeeding (Avert, 2021; Stanford Children's Health, 2021; Chi et al. 2019; and Ezarina & Haris, 2017) but included seronegative children who have lost their parents due to HIV/AIDS (Gregson et al. 2019; Ezarina et al. 2018; dan UNAIDS, 2010). HIV/AIDS and parental death have a direct effect on the AIDS orphan's psychosocial well-being (Li et al. 2015; Sherr et al. 2014; and UNAIDS, 2010). Parents are the children's primary caregivers. Loss of parents to HIV/AIDS leads to full dependence on extended family members as caregivers (Oyeyimika et al. 2020; Mathilda et al. 2015). Therefore, attention should be given to the issue of the full acquisition of AIDS orphan care by the extended family after the death of the child's parents. Studies from Mathilda et al. (2015); Karimli et al. (2012) and Foster, Kozachek and Williamson (2010) have proven that extended families (siblings, grandparents, or aunts and uncles) are fully responsible for the caregiving role after their parent's death.

Furthermore, studies by Oyeyimika et al. (2020) and Silva et al. (2018; 2008) found that the responsible caregivers of these AIDS orphans need to adjust themselves to the existing stigma. The misconception and low level of knowledge about HIV/AIDS have created stigma and discrimination from society against People Living with HIV (PLHIV)/AIDS and their families (Mamukeyani, 2021; Tharshini et al. 2018; Ezarina & Haris, 2017; and Foster et al. 2010). These negativities create gaps in social interaction that can affect the overall psychosocial aspects and economic capabilities of AIDS orphans in the community (Najwa et al. 2018). In this regard, neglect in terms of education, care, and protection, as well as physical and mental health treatment of AIDS orphans, also occurs due to stigma and discrimination. The rejection faced by the orphan's AIDS and their caregivers renders them incapability in

reacting properly, and lowers their quality of life and well-being, leading to a vulnerability in various dimensions (Ezarina, 2008 ; Ezarina & Ismail, 2006).

Apart from that, the caregivers also choose to remain secretive and not to disclose the orphan's AIDS seropositive status even though the World Health Organization (WHO) has suggested the need for them to reveal children's seropositive status during their schooling-aged years (WHO, 2011). The study by DeSilva et al. (2018) and Kiwanuka et al. (2014) found that social exposure would leave a negative impact on children's emotions, doubt, maturity, and ability to understand their health condition. The AIDS orphans and their family experienced aggressive confrontation regarding their health status every time it is discussed (DeSilva et al. 2018; Dwivedi et al. 2015; and Mothi et al. 2012). What matter most is their lack of ability and the difficulties in answering question on the disclosure accurately and appropriately due to the age limit (Kiwanuka et al. 2014; and Vreeman et al. 2013). This literature review shows caregivers as tools or 'nurses' in the home care setting. Thus, caregivers need to be proactive in providing care services, provision of basic needs, and psychosocial support to AIDS orphans after taking over the role (Mamukeyani et al. 2021; Mujjuzi et al. 2021; Najwa et al. 2018; Zikhathile & Atagana, 2018; Mashrom & Rahimah, 2016; Li et al. 2010). This is to ensure quality of life as well as physical and psychosocial well-being of AIDS orphans and caregivers are more secure despite the stigma.

The COVID-19 pandemic has swayed the world with restrictions on movement and anxiety of infection. Many needs are affected by the pandemic. This includes the challenges of meeting the routine need for medication in HIV children when Movement Control Order (MCO) is enforced. All HIV children need to adhere to HAART. Thus, their carers need to make sure HAART drugs supplies are always available even if they were not allowed to leave the house due to Covid-19 MCO. HAART is the acronym for "highly active antiretroviral therapy," to describe the effectiveness of combination drug therapies used to treat HIV. HAART is a therapeutic intervention developed by clinicians and researchers to fight the HIV pandemic (José M. Zuniga, Alan Whiteside, Amin Ghaziani & John G. Bartlett, 2009). It has contributed to a significant reduction in AIDS-related mortality and allowed many previously bed-ridden patients to live healthier, more productive lives. However, HAART adherence imposes demanding routine for the children and their caregivers to cope with, regardless the MCO.

Therefore, this article aims to deliberate the results of a phenomenological study on Strength-based perspective coping strategies by AIDS orphan caregivers. This is to justify how an individual's coping skills involve the strength and resources allocations within the family environment to meet children's needs, increased resilience and assist in recovery and caregiver's wellbeing. The results are expected to bring a positive impact on helping HIV children's caregivers to strengthen the existing coping strategies which were practiced during COVID-19 lockdown period. Additionally, this study foresees a significant contribution to Social Work Practices with families and the extensive action research done to develop a Home-Based AIDS Orphan Care Module.

### **Coping**

Cope is an important component in the process of reacting rationally to stressful events. This process involves a combination of thinking methods (cognition) and individual behaviour in dealing with problems (Brincks et al. 2010; Walsh et al. 2010). Individuals who possess positive coping skills can control existing stress from internal or external sources. According to Nadia & Faridah (2021), coping is a combination mechanism between cognitive and positive behaviour in the selection of the best measures as a solution to deal with problems

or conflicts faced by individuals. Coping can control and overcome stress, anxiety, and depression to manage the state of perception or emotion. Furthermore, the availability to cope well is considered as a behaviour to overcome, reduce, or tolerate threats which suppress the effects of stress when dealing with any problematic situations (Aqilah et al. 2021; Rice & Van Arsdale 2010; Hardy et al. 1994).

Coping is characterized as a response aimed at reducing the physical, emotional, and psychological burden associated with stressful life events. Aqilah et al. (2021) considered the initial assessment of challenging situations to overcome the external burden of self-sufficiency would determine the form of coping strategies used. In addition, studies from Ekas et al (2015), and Blacher et al (2013), stated coping processes have been helping individuals to significantly adapt new skills and ability to deal with the threats, challenges, and life crises. Other than that, these mechanisms also serve as a medium to reduce or moderate the stressor that occurs beyond a person's ability, as well as protective factors to maintain their mental well-being.

Coping skills are a form of strategy adapted by individuals in dealing with emotional, social, and biological stress (Seiffge-Krenke 1998; Lazarus 1993; Frydenberg & Lewis 1991; & Masten et al. 1990). In addition, coping skills refer to a form of the natural predictable way individuals respond when facing any situations which suppress and challenge their capabilities. Thus, the skills become an important element in understanding the long-term functioning of individuals with a history of life conflict including those living with HIV/AIDS (Walsh et al. 2010). In general, Nadhirah and Shahlan (2022); Aqilah et al. (2021); Pull et al. (2013); Brown et al. (2005); Skinner et al. (2003) and Lazarus (1991) classified coping strategies into two main categories, namely problem-focused coping and emotion-focused coping. Problem-focused coping is known as positive problem-solving. Individuals who use this strategy have a positive mindset in dealing with the problems or pressures they face. Whereas emotion focused coping is known as a problem-solving activity that is influenced by either positive or negative feelings. Mayer (2001) has developed two categories in the Model of Brief COPE, namely adaptive and maladaptive coping. Adaptive coping tends to be positively associated with desired outcomes involving active and effective actions (Roming 2018; Folayan et al. 2016; Thompson et al. 2010; Mayer 2001; & Carver et al. 1993). However, maladaptive coping involves dysfunctional actions associated with undesirable outcomes that are negative and lead to lower energy levels and social dysfunction. (Roming 2018; Su et al. 2015; Catz et al. 2002; Vosvick et al. 2002; Mayer, 2001; Carver et al. 1993; Lazarus, 1993; Lazarus & Folkman, 1984).

Many studies have discussed the ability of coping skills involving chronic patients' caregivers regardless of their age and disease background. In general, informal caregivers, especially residential family members, tend to act according to negative feelings rather than positive ones when faced with the impact of caregiving, especially the stigmatized diseases such as HIV/AIDS. However, the study by Tharshini et al. (2018); Dambi (2015); Park (2013); Scallen et al. (2011); and Nilmanat et al. (2004) proved the effectiveness of positive coping skills among caregivers becomes a catalyst in maintaining their psychological well-being when faced with the burden of care. Positive coping develops new hope in patients' lives.

### **Strength-Based Perspective Coping Strategies**

Strength-based perspective coping strategies emphasize more on the form of caregiving positive aspects, and family adaptive coping strategies to existing resources in individual, group, or organizational natural environments. This is to meet the needs, as well as assisting

in recovery and empowerment (Gupta, 2015; Pulla, 2012; Gou & Tsui, 2010; Milet et al. 2007; Pulla, 2006; Saleebey, 2006; Norman, 2000; Phillips & Cohen, 2000). Coping skills that prioritize strength and empowerment include two main strategies: i) emotion-focused strategies, and ii) problem-focused strategies.

### **Emotion-Focused Coping Strategies**

Emotion-focused adaptive coping strategies are divided into several subscales such as i) self-control, ii) positive readjustment, iii) social support (emotions), iv) acceptance of responsibility, v) crisis avoidance, vi) religion (Tharshini et al. 2018; Su et al. 2015). Apart from that, emotion-focused coping strategies are known as the problem-solving reaction by controlling emotional responses. According to Tharshini et al. 2018, the caregiving process for children with life difficulties requires caregivers to be willing and able to shoulder those responsibilities with an open heart and be prepared to face various challenges in terms of emotional, physical, and mental well-being. This action will show caregivers as tools in dealing with caregiving issues without expecting help from the outsider (Foster et al., 2010). Besides, research by Tharshini et al. (2018) states that caregivers are fully responsible for providing basic needs and exhibiting positive behaviours such as self-reliance and self-confidence towards stigma from the global society.

Caregivers can control themselves from being too emotional in dealing with the stress of caring for HIV individuals when they live with the affected individuals in the community (Kimura et al. 2013; Park, 2013; and Fredrickson, 2011). Caregivers and people with HIV/AIDS act actively by restructuring their cognitive and behavioural patterns without expecting help and any support from others. The pressures experienced by caregivers and people with HIV/AIDS encourage them to be more self-confident when dealing with HIV/AIDS psychosocial issues (Oyeyimika et al. 2020; Kohli et al. 2016; Kumar et al. 2015; Mathilda et al. 2015; Makadzange & Dolamo 2011; and Rajwani et al. 2009). Thus, the information on how they successfully cope with previous life crisis episodes is very useful to guide better-coping mechanisms in the future. Validated information is significant for a better definition of risk situations and identifying the best potential solutions (Early & GlenMaye, 2000).

Based on the study reported by Amal & Pandin, (2021); Kohli et al. (2016); Dalmida et al. (2013); Park (2013); Ashton et al. (2005), and Chesney et al. (2003) found that PLHIV/AIDS are coped through social support obtained from family, friends, and professionals. Household environmental factors, emotional support (empathy, love, trust, and caring), and spiritual and religious support help reduce stress while improving the quality of life of individuals infected with HIV/AIDS (Pinho et al. 2017; Cummings et al. 2014; Abebe 2012; Trevino et al. 2010, Faria & Seidl 2006; Neves & Gir 2006). According to Dambi (2015); Park (2013); Brincks et al. (2010); and Rapanaro (2008), continuous social support received by the caregivers from their extended family and social environment is important to balance stress and emotional empowerment throughout the caregiving process.

In contrast, studies done by Oyeyimika et al. (2020); Mohangi & Pretorius (2017); Osafo et al. (2017); Lentoer et al. (2016); Mathilda et al. (2015); Martin et al. (2010) and Silva et al. (2008), has acknowledged the significance of external social support as essential element for coping. This is due to how professional supports build hope and are able to influence individuals positively by combating struggles during the caregiving process. During the long phases of caring for PLHIV, caregivers were reported facing HIV/AIDS stigma, minimal social support, AIDS orphan behaviour problems and hopeless feelings on the recovery chances of the terminally ill family members. A bunch of despair has forced caregivers to react actively and



to seek professional social support services outside of the family (Mamukeyani, 2021; Osafo et al. 2017; Hlabyago & Ogunbanjo, 2009). Social support has been proven to be a strength for those suffering from illnesses (Kirksey et al. 2003; Cobb et al. 2002; & Leslie et al. 2002). Nadhirah and Shahlan (2022); Aqilah et al. (2021); Pinho et al. (2017) stated that religious obedience and spiritual values practices in individuals with prolonged crisis impact is one of the emotional-based positive coping mechanisms. Religious and spiritual elements are proven to be powerful and function to increase emotional and mental stability. The study by Aqilah et al. (2021); Abdul Rashid et al. (2020) states the actions of individuals who place hope and confidence in God can overcome depression and uncertain emotional conditions. This finding is also supported by the study done by Norhayati et al. (2015); Ko et al. (2007); Mattison (2006) where religious coping strategies involving elements of spirituality and strong religious beliefs in health care are associated with a reduction in patient depression (Patel 2002). Emotion-focused coping that is influenced by positive feelings can have an impact on increasing the level of quality of life and psychological well-being of individuals (Finkelstein et al. 2007; Penley et al. 2002).

### **Problem-Focused Coping Strategies**

Tharshini et al. (2018); Su et al. (2015); Walsh et al. (2010); Cooper et al. (2006); and Mayer (2001), stated the subscales involved in problem-focused adaptive coping strategies are planned problem-solving approaches, confrontation, and instrumental support. Problem-focused action strategies are known as problem-solving actions by managing or changing problems. Individuals who use coping strategies focus on positive thinking in dealing with problems or stressors. To address issues of stigma and discrimination and lack of knowledge against HIV/AIDS in the community, the caregivers and PLHIV can obtain scientific information, advice, and professional health care related to the disease through professional assistance (doctors/counsellors /social workers) (Kohli et al. 2016; Hough et al. 2003; Smart, 2003 and Swindells et al. 1999). A well-planned problem-solving coping strategy practiced by the caregivers will overcome stress and increase the ability to adapt to life crises due to HIV/AIDS. Families are also expected to have a positive perception and show an unyielding attitude in dealing with challenges in living as HIV seropositive when they have significant coping mechanisms. (Tharshini et al. 2018; Wood et al. 2007). Besides, Scallan et al. 2011; and Troy et al. 2010, have affirmed that problem-focused coping strategies assist caregivers in regulating emotional reactions and expose them to other problem-solving alternatives while dealing with the stresses of life.

The studies by Mujjuzi et al. (2021); Mohangi & Pretorius (2017); Sharer et al. (2016); Casale et al. (2014); Martin et al. (2010); Chandra et al. (2003); Stein (2003) and Lesar et al. (1995), which involve the HIV/AIDS caregivers also found the tendency to apply problem-focused coping strategies in their daily life, obtain social support such as access to financial and physical resources (foods, and commodities) from other family members, friends, and neighbours. This situation has encouraged the caregivers to continue caring for HIV/AIDS patients. Furthermore, research by Najwa et al. (2018); Constantinos & Ming (2009); Hlabyago & Ogunbanjo (2009); Kumarasamy et al. (2007), and Bharat & Aggleton (1999) agree the rising poverty and financial issues have led the PLHIV/AIDS and their carers to high socio-economic burden, inability to work and living jobless, which lead them to facing the greater challenges in adhering to such a demanding treatment and medication routines of PLHIV/AIDS. Hence, prompted them to cope by seeking instrumental support resources. Professional medical assistance and instrumental support from relatives and friends can improve the quality of life

of PLHIV (Subramanian et al. 2020; OSAMIKA, 2019; Kohli et al. 2016; Fleishman et al. 2003 and Hough et al. 2003) particularly in dealing with the socioeconomic impact stemming from HIV/AIDS.

Active participation in professional networks involving doctors and hospital counsellors or other relevant support groups, helps PLHIV/AIDS with a clearer understanding of the infection issues surrounding a stigmatised disease as HIV/AIDS. Many PLWA managed to build self-confidence when they were in a group. The attitude of individuals who respond positively to HIV infection can indirectly combat the stigma (Kumar et al. 2015). Emotional and instrumental support from family, friends or healthcare professionals encourage PLWA to disclose voluntarily about their HIV seropositive status (Kumar et al. 2015; Corrigan & Rao, 2012; Rao et al. al. 2012; Chandra et al. 2003). This directly helps them to be more rational and confident to speak freely of their needs and rights when seeking medical treatment or any related psychosocial support.

### **Objective**

This article reports on the specific findings from an exploratory study focusing on women living with HIV who were caring for HIV-infected children during the COVID-19 pandemic. The major concern of HIV caregiving during the COVID-19 lockdown was the HIV medication and HAART treatment adherence. Thus, the study was conducted to explore caregivers' coping mechanisms strategies to support and enforce the children's adherence.

### **Methodology**

This study is exploratory in nature and uses a qualitative research design. A flexible study design, which can be modified according to the circumstances and needs of the situation became the priority of the selection of the exploratory study (Hancock et al. 2007) for the topic of AIDS Orphan caregiver coping skills. As HIV/AIDS issues have shown an impact on social symptoms globally, phenomenological studies in a natural context will provide more accurate empirical findings (O'Leary, 2017). This phenomenological study is designed to focus on the essence of how caregivers cope after taking over the role of AIDS orphan caregivers. The design is 'open' and evolving (Nor Aimi & Fauziah, 2019) as well as moving in the natural environment of the informant (Creswell, 2013). Each narrative and explanation from the informants were based on their experiences of being responsive to the needs of AIDS orphan caregiving.

Data collection using the method of in-depth interview, a semi-structured, and narrative approach aimed at studying, exploring, and understanding the lives of individuals as told through their stories and experiences of problems (Schreiber & Anser-Self, 2011; Creswell, 2013). According to Mason (2018) and Yin (2011), this method gives the researcher the freedom to question, explore, extract information, and describe a phenomenon that is studied in detail. One-to-one and open-ended interview techniques with informants were conducted to collect data from the AIDS orphan's primary caregivers. The interview was conducted at the informant's residence due to their social status, research privacy, confidentiality, comfort, and sensitivity (Mashrom, 2021). On average, the duration of each interview session was 45 minutes to 90 minutes for each informant. Interviews were conducted until the required data saturation was reached. Moreover, informants' selection in this research was done by utilising the purposive sampling method. The scrutiny of the appropriate sample refers to non-governmental organisations (NGOs) that agreed to participate in this study. Their details and name are kept confidential.

## Results And Discussion

The data collection of this study was conducted from October 2021 to December 2021 with the initial researcher successfully interviewing four (4) caregivers. All informants are women as shown in Table 1:

Table 1:  
Informants Profile

Informant	Sex	Age	Race	Religion	Marital Status	Occupation	Income
Informant A	F	45	Malay	Muslim	Married	Food Seller	RM 1500.00
Informant B	F	47	Malay	Muslim	Single Mother	Cleaner	RM 1000.00
Informant C	F	57	Malay	Muslim	Married	Clerk	RM 1500.00
Informant D	F	36	Malay	Muslim	Married	Housewife	-

*N=4 persons*

### Coping Strategies based on Strength Perspective

Based on the interviews conducted, researchers found that the informants practised strength-based coping strategies throughout the caregiving period. The caregivers are seen as tools or 'nurses' in the home care setting. This action is considered a catalyst for maintaining the social well-being of caregivers while being identified as being able to provide new hope for AIDS orphans. Caregivers are resilient and were adhered to HIV antiretroviral medication routine for children under their care by i) accepting the children's HIV status, ii) well-planned problem-solving and confrontational approach, iii) receiving continuous social support (emotional and instrumental support) which improvise cognitive restructuring practice and developing positive behaviour based on their past experiences related to HIV/AIDS caregiving challenges.

### Caregiver Acceptance of the Children's HIV status.

Caregiver's acceptance and determination of the HIV exposure status in infants and young children are required to guarantee timely diagnosis and access to appropriate care. The caregivers in this study acknowledged the need to build acceptance of the seropositive HIV status element beforehand. The awareness of how important caregivers' acceptance to their children's well-being was clearly seen from the findings. For the informants, rejection and denial will make it difficult for them to carry out caregiving roles particularly during daily Highly Active Antiretroviral Therapy (HAART) medicine consumption routine. Results showed the caregivers were willing to accept responsibilities and aware of the need to adjust to the children's seropositive status under their care, providing basic needs, and social support once accepting their roles as caregivers.



*“He was still small when I met Baby S for the first time. A cute little 2-year-old boy. He would cry every time he saw me. He refused to be taken care of other than me. I pampered S till I decided to adopt him. I got married and S has been under my custody since then. I underwent a proper legal adoption process. My husband and the whole family accepted S as one of our family members. They love S more than me (laughing). Although they knew he was a seropositive HIV baby, they accepted him very well. I think the way I look after S has inspired them to give the whole support. My siblings have been caring for S as if S is their child. They will bring S wherever they go. Sometimes, I got confused and felt I was the adopted sibling, not S. My family has greater concern for S's health and well-being than they treated me. I think I am the adopted child in the family. Not S (laughing)” (Informant C)*

*“So, I'm with XX during all three blood tests, and all were positive and cried at the clinic. He (the doctor) gave me support and spirit... I accept everything but it is still difficult because I've lost my husband with young children to take care of, and jobless. In my mind who will take the responsibility, I cried in front of him (the doctor). He convinces me by saying I can do this, and not worry because they have medicine. Again, I ask what for? This disease? Yes, but we need to follow the procedure. Doctor always teaches me to be prepared and accept everything that is going to happen. He told me it will be much easier if we accept things from the beginning, thus we need to be prepared and to be ready...” (Informant D)*

These findings are in line with previous studies by Mamukeyani et al. (2021); Mujjuzi et al. (2021); Najwa et al. (2018); Zikhathile & Atagana, (2018); Mashrom & Rahimah, (2016) and Li et al. (2010). The awareness of how important caregiving was to their families, including the responsibility to monitor the children living with HIV medication and treatment routines during the COVID-19 pandemic was prevalent among informants in this current research. For most informants, the understanding of their role as carers for HIV children has held significant meaning of acceptance and is considered a catalyst to cope with HIV-related circumstances. Acceptance in caregiving improves coping skills and has led to families of PLHIV/AIDS physical and psychosocial well-being.

### **A well planned problem-solving and confrontational approach**

Caregivers who practice coping strategies through a well-planned problem-solving and confrontational approach, had decided to face the HAART routine procedures with courage and diligence and were then only able to continue their lives as usual. According to Kohli et al. 2016; Mathilda et al. 2015; Makadzange & Dolamo, 2001; Rajwani et al. 2009; Hough et al (2003); and Smart (2003), this well-planned problem-solving and confrontational approach through professional assistance (paediatricians/nurses/medical social workers/counsellors) has encourage caregivers to obtain scientific information regarding the health care needs related to HIV infection and seeking advice when facing with HIV/AIDS progress uncertainties. Two caregivers thought,

*“So, I asked, what is this medicine for? Is it for reducing the pain? Yes, but we need to follow all procedures. Later, Dr. YY explained the medical team's problem-solving approach, so we stick to the appointment routines although there were pandemic phases before. According to Dr. YY, He will not start the HAART treatment yet... he*

*starts with giving my son and me the supplements first. err mm... again, I confronted him by asking why? The reason for him is to see whether I can schedule my time to take the medicine. Like my case, I must undergo the treatment together with my baby. The doctor must observe how well my kid and my body adapt with the treatment. So, he can proceed with another procedure because these RBD medications cannot be directly consumed. I must undergo the whole-body checkup to see whether I am exposed to other diseases such as TB, cancer, etc. If I directly consume this medicine without treating the other illnesses, it may affect me more. So, I just followed and felt excited, the way he taught me, just like google. I learn a lot. I can even voice my worries and I can always confront the doctors and nurses regarding the planning of my children's HIV treatment, especially when they consult me on the HAART treatment. And I also watched YouTube to gain more information on HIV/AIDS, because I love watching medic tv programs and I do extra readings."*

(Informant D)

*I confront my son whenever he refuses to take pills (medication). I allow him to scold me (get angry), if you get what I mean, before I explain anything about pills and HIV. Sometimes he refuses pills. Not everybody understands what HIV and AIDS are. Once others know you have it, they will leave you dry. That includes spouses. If you are rejected by your own spouse, you will be shunned by everyone, especially those outside the family. I don't want my kid to suffer. We need the support from doctors and the professionals. I always ask S to be careful and always be alert to the surroundings. He is doing well at school. Has many friends, like an ordinary kid. He loves sport and doing well in sports like normal boys at his age. Just that he needs to slow down a bit due to his asthma problem. I can't stop him from participating in outdoor activities and mixing around. He won't like it. Furthermore, I did explain why he shouldn't let any of his friends know his HIV serostatus. No disclosure at all. But as her mother, I always ask the Doctor how to make him obey. Take medication daily. I learn more about HIV/AIDS from doctors and nurses. It makes me feel I am okay, and my kid is doing good if we follow what the Doctor says. I feel less scared also. Confronting whenever appropriate is one way of how we handle and cope with the disease especially when my child refuses to obey the medication routines (Informant C)*

The caregiver's attitude in applying confrontational coping skills indirectly combats the stigma of HIV/AIDS. The PLHIV/AIDS network with a professional setting comprising doctors, nurses, and other related health professionals: i) social workers, ii) hospital counsellors, and iii) support groups can increase HIV/AIDS patients' knowledge and understanding of any pertinent HIV challenges. Caregivers who choose this mechanism of action were found to be successful in building self-confidence, especially to disclose status voluntarily (voluntary disclosure) as well as to obtain social support. Mutually, self-confidence has extensively contributed to increasing the caregiver's ability to execute HAART procedures diligently and subsequently continue daily lives despite the demanding routines.

### **Continuous Social Support (Emotional and Instrumental Support)**

Emotional and instrumental support from family, friends, and health professionals encourages PLHIV to be more courageous in disclosing their HIV infection status to family and friends. This directly helps them to think rationally despite having to adhere to a strict schedule of treatment as well as medications.

Social support indicators such as trust, acceptance, love, and care from family members and friends, motivate caregivers to be more self-confident in caring for AIDS orphans.

*"My son has a close relationship with my family compared to my husband 's side. My family accepts us although they know we have HIV. No rejection. I think that motivates me to live my life as how a normal parent will. I believe things are going to be fine and I can look after my kid like how other parents do. I don't feel rejected by my family, and my rights as a family member have never been denied as well. All because of their support. Meaning, I don't lose my family with all the things happening in my life, what ALLAH tested me with. My family is the biggest support I have. They still accept me even though I have committed a sin and discomforted them with what I've done. They love my children as well."*

(Informant C)

The attachment between informants and friends who are also taking care of HIV-positive children causes their relationship to remain stable despite not seeing each other face-to-face during the movement control order. Their relationship is stronger especially when the HAART medication stock at home is reduced, and they are anxious to apply for hospital and pharmacy visits. This is due to the application method for MCO where everyone needs to get permission from the police to move from certain locations to another. Thus, it will cause them to disclose their HIV status to the police and they are not willing to take such a step. This study found that informants have been contacting friends who have stock of HIV drugs at home and to borrow whenever they run out of drugs during the MCO. In the early phase of the pandemic, the informant admitted that it was difficult to go to the hospital to get the HAART supply. They don't want to reveal their HIV serostatus to police officers to get permission to go to the hospital. Although the Ministry of Health confirmed that HIV drugs can be delivered by hospital staff to the informant's home, the interview results found that all the informants were unaware that this facility was available. For this reason, informants have borrowed drugs from their friends who are also guardians of HIV children to ensure they do not lose their supply of medicine. Borrowing means they are willing to return the medicine after the MCO ends. The informants agreed that sustaining HAART drug stock at home by borrowing it from friends who were also looking after HIV children, was the best solution and the most convenient coping mechanism during MCO.

Accordingly, emotional support obtained from professionals such as doctors, counsellors, psychologists, or social workers was found to help reduce the stress while improving the morale, quality of care and treatment compliance (HAART routines) not only among the caregivers but also among the children living with HIV.

*"We need regular counselling services. If not, we won't survive. We prefer to be in a support group where we can meet and hang out with others who face the same issues. Surrounded by a good supportive network. We want to join activities with those who look after children with HIV. We can share and they surely understand us."* (Informant A)

*People like us need emotional support. My kid needs a psychologist, and I myself also need help. We've been referred to the counsellors and psychologist from the day we*

*know the status. I also asked for help outside. I asked an NGO to help me. I go and ask by myself. Because I have HIV children and their father was sick at the time. Can you imagine how tough it was? I'm going through this stage on my own. I do all kinds of jobs and house chores. My husband is the breadwinner, and he must work for money. (Informant B)*

*"So, the day my kid was admitted. Can you imagine how I can take care of my sick child while my firstborn is also under my care, and she does not have HIV. I've no other way other than to speak to Dr. XY and ask for his permission to bring along my other child while I am here to take care of the other. They have informed me about procedures XX that need to be followed, plus my in-laws are not around. They all work, and no one is at home, that's why I must bring him. Then he said OKAY, lucky I found a very supportive, understanding, and helpful doctor. (Informant D)*

This statement can be supported by previous studies, Oyeyimika et al. (2020); Mohangi & Pretorius (2017); Osafo et al. (2017); and Silva et al. (2008). Emotional support is an important element to boost motivation and wellbeing. It gives strength and hopes for the caregivers to respond positively and feel attached in caring for AIDS orphans. Factors contributing to emotional support such as empathy, love, trust, and care help to reduce stress and improve the quality of life of individuals infected with HIV/AIDS (Cummings et al. 2014; Abebe 2012; Trevino et al. 2010, Neves & Gir 2006 and Prado et al. et al. 2004).

This study also found that some caregivers have more confidence in accepting AIDS orphans as their wards when they receive instrumental support.

*I send S to a private religious school, fully funded by one NGO. I don't have the money. Even though I am his guardian, the NGO covered all the school expenses. They look after his welfare as well. I give him love, prepare all the necessities. He receives a school entry incentive, food coupon, and school uniform. I can't afford to provide all the money needed. My husband's income is not enough. He only gets daily pay. The financial aid and all donations really help us to provide a better living for S. This includes all the medication he receives from the hospital. (Informant C)*

Najwa et al. (2018); Constantinos & Ming (2009); Kumarasamy et al. (2007) and Bharat & Aggleton (1999) explained that the poverty and financial issues that arise because of being unable to work, losing a job, bearing the burden of the cost of living, treatment and medication for HIV/AIDS patients, prompt them to find instrumental support sources. Instrumental support sources such as financial and physical aid resources (material needs and basic commodities) obtained from other family members, friends and neighbours are one of the strength perspective coping strategies identified among HIV/AIDS caregivers (Mujjuzi et al. 2021; Mohangi & Pretorius, 2017; Sharer et al. 2016; Casale et al. 2014; and Stein, 2003). Material resources, financial aid, and medical assistance improve the quality of life of HIV/AIDS caregivers and PLWHAs (Subramanian et al. 2020; OSAMIKA, 2019; Kohli et al. 2016; Fleishman et al. 2003; Hough et al. 2003 and Swindells et al. 1999). (Subramanian et al. 2020; OSAMIKA, 2019; Kohli et al. 2016; Fleishman et al. 2003; Hough et al. 2003 dan Swindells et al. 1999).

Therefore, individuals or caregivers who seek continuous social support from family members and the social environment (friends/professionals) can bear with stress and learn to strengthen their emotions (Amal & Pandin 2021; Kohli et al. 2016; Dambi 2015; Park 2013; Brincks et al. 2010; & Rapanaro 2008) throughout the period of care while also being able to give lives a new hope.

### **Practising Cognitive Restructuring and Developing Positive Behaviour Centred on Their Past Experiences Related to HIV/AIDS Caregiving Challenges**

This study has also revealed the significance of medical team-patient's supportive relationships in sustaining family adherence to HIV-HAART continuous treatment. Previous knowledge of managing HIV stigma, health deterioration and past life crises due to HIV rejection is useful in building a better coping mechanism. The ability to react by referring to professional resources and reviewing past medical experiences is very important to determine the best potential solution for any problematic situation. Successful professional support can reduce caregivers' dependency on others, where they will feel more confident with treatment procedures as well as medications for patients. HIV/AIDS is synonymous with the uncertainty of the progression of the virus in the body as well as possible death. Thus, this has made caregivers to be very sensitive to medical support.

Health professionals do not only involve the doctors but also nurses, social workers, and counsellors. These findings are parallel with a study by Kimura et al. (2013); Park (2013); Fredickson (2011) and Early & GlenMaye (2000). The controllable caregivers, from being captured in emotional trauma while handling seropositive individuals in the community, tend to have higher strength in coping skills and are actively involved in cognitive reshaping and positive behaviours over time.

*My youngest son is still under medical observation. Once my HIV seropositive status was confirmed and I adhered to a long-term PreP (HIV medication regime) treatment, my viral load decreased to zero viral load and I tried to get pregnant. My husband (from her second marriage) is seronegative. He is not infected although we have a great marriage life. I protect myself and obey what the doctor asks me to do. I got pregnant and my pregnancy is thoroughly monitored by doctors. When my baby was born, he was also observed until today. Once the Doctor knew I was pregnant, I must take certain medication, meant for protecting my baby from getting infected. He must drink one syrup every six hours from day one till he reaches 6 months old. He was under medical observation till he reached two years' old. They did another blood test. The test turned out negative, we confirmed the baby is not infected with HIV. From that point I understand that HIV transmission during birth can be prevented. I am very confident I was wrong all this while because I think HIV is easily transmitted. Now I know better. I can think better, and I will look after my son. We will be fine. I have changed the way I think about living as a positive HIV mother. I have a good life now. Better, indeed.*

(Informant A)

*Every time we go for medical appointments, doctors will explain how I should take care of myself and my kid. He advises good food choices and to be more concerned about our emotional wellbeing. Like last time we went for a check-up, the Doctor reminds us not to consume too much junk snacks and be careful with my son's snacking choices.*



*We need healthy food instead. As an HIV positive child, my son needs fresh healthy food, less preservatives, and avoids processed food to make sure he has the energy to stay healthy and fight any disease associated with HIV children. However, my son has this problem where he is reluctant to eat vegetables and I need to force him every time. If not, he won't eat green vegetables at all. I admit it has been tough to make him eat green vegetables (the informant smiles when sharing this information). Sometimes I create a more dramatic explanation, yet no luck. He won't have it."*

(Informant C)

Interviewed informants also admitted that hospital staff, especially doctors, will help them deal with fear, especially when there is a need to explain to children why they must continue to take HAART for life.

*It's like I want to tell him directly (disclosure status), but I'm not strong enough. At that time, even the doctor and nurses had explained to him why he must undergo treatment and take medications. I don't know how to explain. In fact, I really can't. Because we think we ourselves can't easily accept the disease, it's not that we can't accept it; we can accept it. But we think if it is hard for us to accept, it will be the same for the children. It is hard for them as well. That is what we think, and we can't tell them the truth. It was hard. We never blame this disease; don't blame that he has it. We are afraid that he cannot accept it. We are afraid of the future because we are facing the stigma and we are afraid others will do the same and they will ignore him if they knew he has HIV; Being HIV positive children is not his fault either. Haa, but we had explained it in a more proper way. Well, at least we think it is more proper than disclosing the truth. I told him that the routine medicine is a vitamin, then sometimes he has friends come to house and they know about it, they will say it's okay to take medicine. As a caregiver, I must be sure to say that this is not a medicine; this is a vitamin. He must have understood the medicine as a vitamin and supplement. Just say Amir must take this vitamin which makes him strong.*

In contrast to the study of Oyeyimika et al. (2020); Kohli et al. (2016); Makadzange & Dolamo (2011); and Rajwani et al. (2009) who explained that caregivers become more self-confident to face the issue of HIV/AIDS due to the pressures of life experiences, this study reveals the importance of medical team-patient's supportive relationships in sustaining the family adherence with HIV continuous treatment. A good coping strategy is expected to function as a provision of strength which helps caregivers continue their daily life as usual despite the pressure (Kumar et al. 2016). PLHIV/AIDS (PLWHA) who are involved in a supportive network with medical professionals (doctors and hospital counsellors) and other PLWHA are documented to have a better understanding of HIV infection and practise positive living mainly because the supportive network develops self-confidence among the members. There are also some negatives findings from the above interviews and has been incorporated in the analysis and evaluation as well. What can be mentioned is the positives greatly outweigh the negatives.

### **Summary And Suggestion**

This article has summarised the coping strategies practised by caregivers who have taken full responsibility for caring for AIDS orphans during the COVID-19 Movement Control Order

(MCO) phase. Women living with HIV, who are also caring for HIV children in this study practised strength perspective-based coping strategies. Coping skills that prioritise strength and empowerment include two main strategies i) emotion-focused strategies and ii) problem-focused strategies. All HIV children need to adhere to HAART. Thus, their carers need to make sure HAART supplies are always available even if they were not allowed to leave the house due to Covid-19 MCO. The finding of this particular study has identified that all caregivers are resilient and adhere to HIV antiretroviral medication routine for their children under their care by i) showing acceptance of the AIDS Orphans' seropositive status, ii) well-planned problem-solving and confrontational approach, iii) receiving continuous social support (emotional and instrumental support) and iv) practising cognitive restructuring and developing positive behaviour centred on their past experiences related to HIV/AIDS caregiving challenges. Based on the results, it can be concluded that family acceptance towards the caregiving responsibility has secured the quality of life, mental health, and emotional as well as physical and psychosocial well-being of AIDS orphans and their caregivers. Furthermore, the emotional and instrumental support received from medical professionals has greatly helped caregivers deal with any crisis events during the COVID-19 lockdown period which also includes not skipping on HAART medications. HIV caregiving is indeed a struggling life crisis. Nevertheless, the confrontational coping strategies practised reflect the caregiver's acceptance towards the caregiving role with full of courage, confidence, and resilience. The results are expected to have a positive impact on helping caregivers to strengthen their existing coping strategies. Additionally, this study foresees a significant contribution to Social Work Practices with families and the need to develop a home-based AIDS Orphan care module.

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