PriMera Scientific
Medicine and Public Health
Volume 9 Issue 5 November 2026
ISSN: 2833-5627

Share the Care Systems: Empowering Women Caregivers of Children Living with HIV and AIDS in Rural Malawi through Process Innovation

Type: Comprehensive Review
Received: September 30, 2026
Published: November 11, 2026

Citation:
Mandayachepa Nyando. "Share the Care Systems: Empowering Women Caregivers of Children Living with HIV and AIDS in Rural Malawi through Process Innovation". PriMera Scientific Medicine and Public Health 9.5 (2026): 26-41.

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Introduction

Eighty-five percent of the population lives in rural areas of Malawi, and over 12% currently live with human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS). Approximately 88, 000 children are living with HIV and AIDS (Nutor et al., 2020). In response, the Malawian government's clinical approach and HIV/AIDS policy place a special emphasis on children's health (Malawi Government, 2018). As a result, every child receiving clinical services is tested for HIV and AIDS. Maternal and female care are not given top attention in screening or treatment programs. The health of women and children in Malawi may be affected by this policy. That is, because a child's survival depends on the health and well-being of their mother or other primary caregivers, their chances for a fulfilling life are interdependent (Mabetha, De Wet-Billings, et al., 2023).

Despite the remarkable success of Malawi in recent years in containing and lessening the effects of the epidemic, according to the United Nations AIDS Programme (UNAIDS), 2020, the prevalence of (HIV) is one of the highest in the world. According to estimates, 9.2% of adults in Malawi (aged 15-49) have HIV, one of the highest rates in the world (Nutor et al., 2020). According to the United Nations AIDS Program in 2021, 1.1 million people in Malawi had HIV (United States Agency for International Development, 2021). The Malawian HIV epidemic has affected the country's life expectancy, limiting me to 61 years and 67 years for women (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2020). Young people are particularly at risk due to early sexual activity and marriage, with around one-third of all new HIV infections in Malawi in 2018 occurring among young people (ages 15-24). Despite this, approximately 60% of young people do not have sufficient knowledge of how to prevent HIV infection (UNAIDS, 2020).

HIV prevalence among adult women (aged 15-64) is among adult men. These findings demonstrate that HIV infection disproportionately affects women in Malawi. This disparity is especially prominent among 25-29-year-olds, as HIV prevalence is three times higher among women than men in this age group (13.6% vs. 4.7%). Most new HIV infections occur in young individuals (UNAIDS, 2020).

Less than one-third of all new HIV infections (14,000 of 38,000) in Malawi in 2018 occurred in young people (aged 15-24). Approximately two-thirds of new infections among young people were among young women (9,900 new infections among young women compared to 4,200 among young

men). In 2018, 4.3% of young women were living with HIV compared with 2% of young men (UNAIDS, 2020). Awareness of status is particularly low among HIV-positive young people, with around 67% of HIV-positive men aged 20-24 and 58% of HIV-positive women aged 15-19 unaware of their status (Malawi Ministry of Health, 2016).

Malawi's national HIV response was evaluated by the Malawi Population-based HIV Impact Assessment (MPHIA 2020-21). According to the report, 8.9% of adults in Malawi have HIV and 946,000 of them are adults (Hendery, 2022). Between the ages of 20 and 39, the prevalence of HIV was twice as high among women as it was among men in each age group. Until women's late 40s and men's early 50s, HIV prevalence often rose with age (Hendery, 2022). According to study findings, 88.3 percent of persons with HIV were aware that they were positive for the virus. 97.9% of persons with HIV who were aware of their status were receiving antiretroviral therapy (ART), and 96.9% of those receiving ART had suppressed viral levels. According to these findings, Malawi has already achieved the second and third UNAIDS 95-95-95 targets before the target year of 2025. The first 95 target, which calls for ensuring that 95% of people with HIV are aware of their status, is still below that mark (Hendery, 2022).

Due to new international initiatives, the number of people receiving HIV medication has substantially increased recently, especially in countries with limited resources, such as Malawi, enabling the ongoing care of persons living with HIV and AIDS (UNAIDS, 2020). In 2018, 62% of HIV-positive individuals had access to treatment. Female carers need informational help as well as psychological, physical, and emotional care. Of these, 53% showed viral suppression. Before using any type of health service, a person must be tested for HIV and those who are positive should start taking antiretroviral medications immediately. Through a strategy known as home-based care, families bear a large portion of the cost of providing care to those living with HIV and AIDS. Once the patient has stabilised, they are sent home to be looked after by their relatives. Families are in charge of this with occasional professional assistance from healthcare professionals. To lessen the difficulties women caregivers, encounter while caring for their children with HIV and AIDS in a context with few resources, this paper will discuss the new model created for rural regions (homes).

HIV and AIDS patients have a complex multisystem disease process, invasive diagnostic testing, multiple hospitalisations, and a very high mortality rate. Hospital-based care services are particularly strained by these clinical features. Community-based services are strained by inadequate financial and social reserves and the lingering fear of contagion associated with the epidemic.

Regarding dissimilarities, particularly the care and support devoted to healthcare and psychosocial support, layouts bear the fact that people caring for an infected person with HIV, particularly those who have developed AIDS, are family members. In some instances, their care needs are similar to those of other patients with catastrophic or terminal illnesses such as cancer. While focusing on HIV-related needs, care is different because caregivers believe that the healthcare system should strive to provide a desirable level of care for all patients, including those on the home-based care model; however, this is not the case in rural Malawi.

Objectives of the paper

The overall objective of the project was to develop, test, and validate the Share Care Model. The specific objectives of this study are as follows:

1. To analyse the challenges in providing support services to caregivers, including HIV/AIDS patients.
2. Creating learning issues and sharing experiences
3. To examine the current provision of support services.

Theoretical Framework: Jean Watson's Theory of Human Caring

According to Watson (1997, pp. 50-51), the core of the Theory of Caring is that "*humans cannot be treated as objects and that humans cannot be separated from self, other, nature, and the larger workforce*". Her theory encompasses the whole world of caring, with an emphasis on the interpersonal process between the caregiver and care recipient. The theory focuses on the centrality of human caring and on the caring-to-caring transpersonal relationship and its healing potential for both the one who is caring and the one who is being cared for. The structure for the science of caring is built on ten carative factors.



Figure 1: Jean Watson's Theory of Human Caring 1997.

Watson postulated that at the centre of caring is the person to care for and to be cared for. Therefore, for care to be effective, certain compelling factors must be considered. The first is to Embrace, where altruistic values and the practice of moving, kindness with self, and others are paramount to the caregiver and care provider. The second is the Inspire, where the caregiver instils faith, hope, and honour in others, especially those being cared for. Trust is important as Watson sought to be an essential factor in caring, where the self and others develop by nurturing individual beliefs, personal growth, and practices.

In the process of delivering care, nurture is inevitable because, according to Watson, there is a spirit of Helping, Trusting and Caring relationships that develop between the caregiver and the cared. Forgiveness is an aspect of the care delivery process. This is where there are positive and negative feelings and authentic listening to another's story. Deepen is where individuals in a group solve unison problems together by sharing their experiences. This is the spirit of the Share Care Model, in which a group of individuals solves problems by sharing experiences and learning from one another. This leads to amicable decision-making. Watson regarded Decision Making as a key factor in caring and caring.

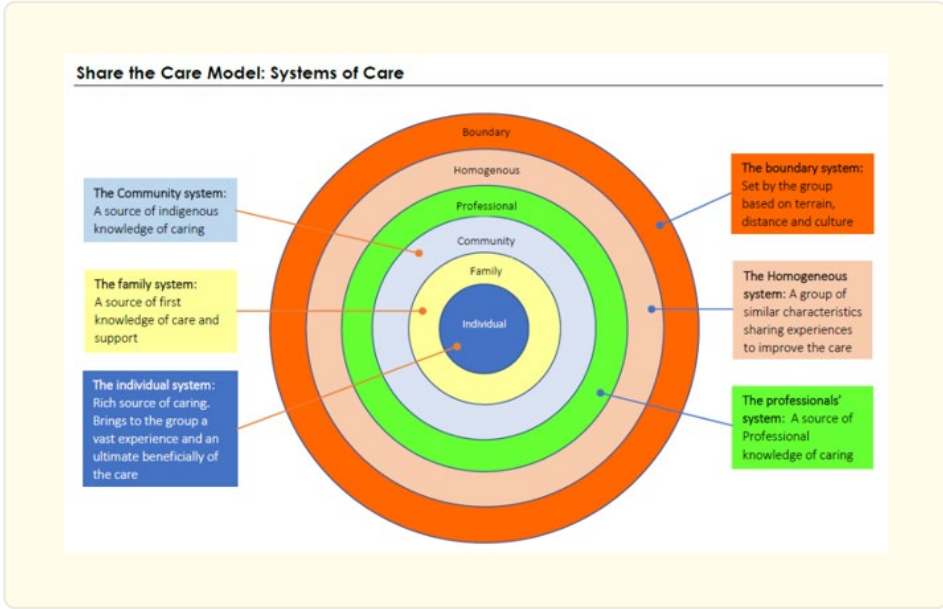
Description of the innovation

The relevant research question for this model was formulated as follows: Is the prototype solving the problem in the best possible manner? This is a step-by-step realisation of how the prototype works by conducting the process. The next steps were as follows:

1. The problem was identified as the caregivers' lack of support in caring for children living with HIV and AIDS in Rural settings.
2. Using the design thinking approach (step-by-step), the problem was analysed, leading to pointers to sketch a prototype.
3. Several meetings and workshops were conducted to refine the Share the Care Model
4. Testing the Share Care Model is a continuous process.

The Share the Care Model incorporates a systems-of-care approach with six distinct systems. The first system, the boundary system, involves a group of individuals agreeing on demarcations to enhance their concept of care through shared experiences. It establishes a shared group within a rural setting. The second system, the community system, mobilises community resources to support caregiving, utilising various forms of support such as human capital, material resources, and emotional assistance. The professionals' system relies on different professions within a specified boundary to provide professional support to the care-sharing groups. The family system is unique in this model, acting as the unit that connects all systems. It encompasses the individual's upbringing, education, and cultural norms, with the family playing a central role in enculturation. The homogeneous system involves forming groups of individuals with similar characteristics to provide care and establishing boundaries and rules for efficient management. Lastly, the individual system recognises each person as a system in their own right, with care being influenced by their unique experiences and serving as a source

of learning for others.



The systems of care within the Share the Care model offer advantages such as a comprehensive approach to caregiving, utilising community resources, and empowering individuals. By considering multiple dimensions of care and engaging various stakeholders, the model aims to provide holistic and collaborative care. However, there are also potential disadvantages to consider. Challenges may arise from the complexity of coordinating different systems, the lack of standardisation in care practices, and the potential for fragmentation. Additionally, resource limitations and cultural barriers can impact the accessibility and inclusivity of care within the model. Critical evaluation and careful implementation are necessary to optimise the benefits of the Share the Care model while addressing these potential drawbacks.

Prototype testing stages

The model was put into four zones and Table 1 outlines the prototype testing stages, stimuli used, fidelity level, and the recommended session type for each stage. The testing model is divided into three stages. In the first stage, the stimuli are vague ideas that are not yet documented. The fidelity level is very low, and the best session type is unmoderated. In the second stage, the stimuli are ideas that have been documented on paper. The fidelity level is low, and unmoderated sessions are still recommended. In the third stage, the stimuli are sketches that make sense. The fidelity level is high, and moderated sessions are suggested, with the complexity determining the extent of moderation required.

Stage	***Stimuli***	***Fidelity***	***Best session type***
First stage	Vague ideas not on paper	Very low	Nothing moderated
Second stage	Ideas on paper	Low	unmoderated
Third stage	Sketches making sense	High	Moderated depending on the complexity

Table 1: Prototype testing stages.

Literature Review

The current state of care in Malawi

The HIV and AIDS epidemic is a major challenge to public health and socioeconomic development in Malawi (Malawi Ministry of Health, 2016). Currently, it is the greatest threat to human development in the country and a major contributor to poor performance in various sectors (Ameh et al., 2020). It continues to cause great suffering for the people of Malawi in terms of physical, psychological, and emotional devastation. The spread of this disease is so pervasive that it threatens the most productive groups in society (Pasipamire et al., 2018).

In Malawi, public services are a critical part of the government's executive arms (UNADS, 2020). Poor Public Service performance has a direct adverse effect on national development efforts (Malawi Ministry of Health, 2016). The United Nations Development Programme (UNDP) and UNAIDS, the government commissioned the Malawi Institute of Management to undertake an HIV/AIDS impact assessment study in the Public Service (NSO, 2015-2016); UNAIDS, 2020; Malawi Ministry of Health, 2016). The report revealed that HIV/AIDS is the major cause of death in public services and among people living in rural areas of Malawi (National Statistical Office - NSO/Malawi and ICF, 2017). The report recommended the introduction of HIV and AIDS prevention and mitigation measures for a sustained reduction in the incidence of the disease across the entire population of Malawi (National Statistical Office - NSO/Malawi and ICF, 2017). This included a deliberate effort to target the population living in rural areas of Malawi, where there are limited resources to mitigate the impact of HIV and AIDS.

Until recently, there has been no assessment of the impact of HIV and AIDS epidemics on the public in Malawi to enable the government to adopt feasible and sustainable interventions and formulate human development policies and succession plans (National Statistical Office/Malawi and ICF, 2017; National Statistical Office Malawi and ICF Macro, 2011)). The national response to the impact of HIV/AIDS calls for cooperation among Malawians to reduce the HIV/AIDS epidemic. Today, Malawi is facing grave threats in the hope of attaining full and sustainable development (Malawi Ministry of Health, 2016). One such challenge is HIV and AIDS, which have placed a virtual stranglehold on the present and are well on the way to compromising the future (Worthington et al., 2020). However, the Government and people have decided to confront this problem (MDHS, 2016; Worthington et al., 2020). Hence, there is a need to develop plans that consider the situation on the ground and that allow for greater sharing of care within and among community members.

Current/past methods of care

Some models have been used in Malawi, focusing on different sectors of society. One of them is the country-wide system of 28 One-Stop Centers known as '*Chikwanekwane*' (everything under one roof) to provide medical, legal, and psychosocial services for survivors of child maltreatment and adult intimate partner violence. Youth-friendly services are another hospital-based model in which youths gather to discuss and share their experiences regarding their lives, including health issues. This is a one-stop centre for youth to access sexual and reproductive health services, including HIV, AIDS, and sexually transmitted infection services (Malawi Ministry of Health, 2016). These services typically entail a room where individuals stop in and receive counsel about HIV, STIs, contraceptives, and tests. Youth-friendly services are mostly hospital-based. However, other models complement this facility in other areas of the population, such as Youth Clubs in secondary schools. However, the Ministry of Education does not allow for the distribution of some contraceptive methods, such as condoms, within school premises.

Limitations of current methods

The rapid spread of HIV and AIDS throughout sub-Saharan Africa has significantly worsened the continent's orphan epidemic. To ensure that global community initiatives are culturally acceptable, knowledge of African solutions to issues is necessary. The Share the Care Model is a novel concept for less educated rural populations. It is intended to assist female caregivers in learning from one another how to care for sick wards with resources that are readily available locally.

Community-based orphan care, institutional and residential care, and self-care are the three main approaches to health care in Malawi. Many Africans like community-based care models because they keep children in their natural family settings in their villages and tribes and, most importantly, because they are culturally appropriate. A technique to lessen the effects of disease on communities in Malawi is through the communal sharing of information and tasks. For instance, if a child or adult member of the family has a chronic illness, other family members and people in the community help the family by gardening or providing food and other essentials. These lessen stress on the family members in charge of caring for the ailing members of the family. It is necessary to consider specific cultural behaviours that are contrary to the ideal method of care for chronically ill children within families and communities. It is frowned upon in some tribes, particularly in the ruling Chewa tribe, for children to openly discuss their sexual practices with their parents. This could have several effects when youngsters become older. Another common custom is the requirement for girls to have sex with an elderly person once they have reached puberty. By engaging in this behaviour, the girl exposes herself to STIs, such as syphilis and HIV.

Methods

Data collection

To test the prototype, the innovation of the Share the Care Model included a group of female caregivers of children with HIV and AIDS. The most frequently used methods for data collection were observations of each group member in the homes, informal discussions, and participant observations. These methods proved to be ideal as participants were free to talk. The data collector appeared to be one of them and that made the women freer and relaxed, and hence, able to release information. The average distance from the hospital where they access HIV and AIDS support to their homes is an average of eight kilometres and most of them walk through. The field visit to their homes made the data collector appreciate the terrain and distance covered by the women to reach the meeting place. It also reveals the degree of poverty for each family but at different levels. The visits also concretised empathy with communities to understand the problem in depth and defined it with women at their respective homes. This is a key stage in human-centred design research. During the ideation stage, the researcher held meetings with professionals to develop a Shared the Care Model.

Design Thinking Approach

Design thinking is becoming an incredibly popular approach to innovation, and requires a change in one's mindset (Bazzano et al., 2017). Individuals who want to innovate their work and create better experiences, products, and services for their customers or users may benefit from utilising certain behaviours and attitudes that can refresh and empower their creative thinking (Steen et al., 2011). The change in mindset concerns the ability to learn from failure and use failure as a tool to improve my practices, and not vice versa. The process was performed using the design-thinking approach, which is in itself a human-centred design as shown in Figure 2.

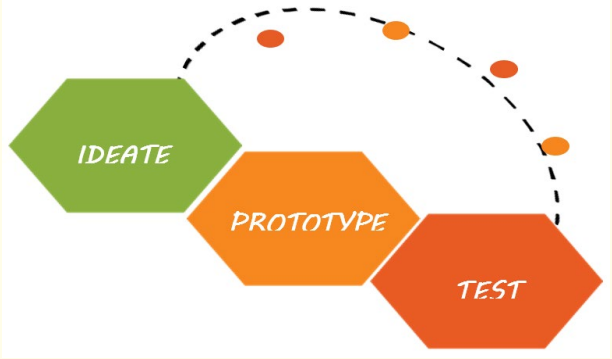


Figure 2: Ideating, prototyping, and testing an idea.

Findings

Table 2 shows the 22 pseudonymised study participants with various characteristics.

Pseudonym	*Marriage experience*	*Place of care*	*Caregiver's age in years*	*Child's age in years*	*HIV status*
Mayi Salima	Widow- Polygamy-husband died of HIV and AIDS	Home and hospital	34	3	HIV + on ARVs
Mayi Kasangadzi 4	Polygamy First wife –husband alive	Home and hospital	26		HIV + on ARVs
Mayi Bua	Monogamy-Stable-husband alive	Home and hospital	34	2	HIV + on ARVs
Mayi Dedza	Widow- Husband died of HIV and AIDS	Home and hospital	32	8	HIV + on ARVs
Mayi Dowa	Monogamy Second marriage- husband alive	Home and hospital	36	5	HIV + on ARVs
Mayi Lilongwe	Monogamy-husband live	Home and hospital	40	8	HIV + on ARVs
Mayi Kasungu	A grandparent Widow- husband died-	Home and hospital	70	11	Granddaughter - HIV + on ARVs
Mayi Muyeza River	Widow-Husband died, HIV + on ARVs.	Home and hospital	32	4	HIV + on ARVs
Mayi Mtiti		Home and hospital	46	11	HIV + on ARVs
Mayi I	Widow, husband died of HIV, she had HIV+	Home and hospital	36	2	HIV + on ARVs
Mayi F	Monogamy, the second husband, refuses an HIV test	Home and hospital	28	3	HIV + on ARVs
Mayi B	In Monogamy, the husband refuses an HIV test	Home and hospital	31	9	HIV + on ARVs
May C	In Monogamy, the husband refuses an HIV test	Home and hospital	34	7	HIV + on ARVs
Mayi Kasangadzi	Widow, husband died of HIV and AIDS, she is HIV +	Home and hospital	29	6	HIV + on ARVs
Mayi Nsanje	Monogamy grandparent	Home and hospital	79	6	HIV + on ARVs

Mayi Mzimba	In the second monogamy husband refuses HIV Test	Home and hospital	33	6	HIV + on ARVs
Mayi Mpanda 3	monogamy - husband HIV+	Home and hospital	26	4	HIV + on ARVs
Mayi Mpanda 2	Widow, HIV +	Home and hospital	39	5	HIV + on ARVs
Mayi Mantcheche	Monogamy- husband HIV	Home and hospital	39	11	HIV + on ARVs
Mayi Lusa	Monogamy Husband alive and HIV+ but not on ARVs yet	Home and hospital	46	11	HIV + on ARVs
Mayi Ntchisi	Monogamy, husband alive and HIV + happy marriage	Home and hospital	35	6 years	HIV + on ARVs
Mayi Zomba	Widow, husband died of HIV and AIDS, she is HIV +	Home and hospital	34	5 years	HIV + on ARVs
Mayi Mpanda	Widow, husband died of HIV and AIDS, she is HIV +	Home and hospital	22	6	HIV + on ARVs

Table 2: Characteristics of the study participants.

Our findings were categorised into themes following a thematic analysis of the invisible and unrecognised care of female caregivers of children living with HIV and AIDS in rural Malawi, revealing several key themes.

Theme One: Burdens and Challenges

This theme encompasses the various physical, emotional, and financial burdens that female caregivers experience. The subthemes included the impact of caregiving on health and well-being, financial strain, stigma, and discrimination faced by both caregivers and the children they care for.

Subtheme: Re-kindling emotions-HIV and AIDS counsellor takes over

Some caregivers were unaware of how they had been identified as HIV positive. However, they briefly defined it and discussed it as HIV-positive. For instance, Mayi Lusa described having HIV without going into detail about how she was identified with the disease. She responded quickly, despite my prodding. She could not explain why she had been diagnosed with HIV; all she could say was that she had HIV. She only responded that she had HIV during the stigma discussion, although this was not a direct response. When she states that she "*am also touched*" she was admitting that she was HIV-positive. She further stated that the child's father was also "*touched*" meaning that the father was also HIV positive. When she described that "*let us be like the way we are maybe it's our bad luck*" she was lamenting and she stated her situation while sad. She stopped talking because she was crying and became tearful, thus ending the discussion. Arrangements were made for immediate counselling of qualified HIV and AIDS counsellors.

Another example is Mayi Mzimba, who discovered that she was HIV-positive when "*her child was sick*" and had gone to the hospital for treatment. She also stated that while at the hospital, the child was tested for HIV, and the results were HIV-positive. The hospital staff then asked her to be tested for HIV following the child's HIV seropositivity. She accepted that the HIV test results were positive. However, Mayi Mzimba stated that her husband did not want to go for an HIV test because he thought he was "*normal*" and blamed his

wife for bringing HIV and AIDS into the family. She explained that he "*refused to take the HIV test*" and he had no immediate intentions to do so.

Sub-theme: Caregiver's emotions running high

Four female caregivers were diagnosed as HIV-positive during routine pregnancy-screening procedures to protect the unborn child. Mayi Dowa was one of the four female caregivers who discovered that she was HIV-positive when she was pregnant. She stated that "*she had the HIV test when she was pregnant and the results were HIV positive*". Mayi Dowa explained that she could not attribute her child's illness to her HIV-positive status because she felt that "*she had followed all that was required during pregnancy and delivery for the child to be HIV-negative*". "*They asked me if I had taken the medicines before the labour started, and I said yes, I did drink the nevirapine*". "*Nevirapine*" is the antiretroviral (ARV) drug of choice in Malawi, which is still being used to prevent the transmission of HIV from mother to child while still in the womb. That was an emotional time for her, as she explained that "*I was very sad and I started crying because I followed what was required for my child to remain without HIV*. She reported that she received "*nevirapine*" during pregnancy and at delivery, and therefore expected that her child would be HIV negative and not HIV positive, as the situation had been.

Mayi Dowa contended that by that time she had been going to the hospital frequently because her child was getting sick too often and the hospital staff could only give the child "*ant malarial treatment or certain medicines to stop the cough for the child*". Mayi Dowa further described that even hospital "*staff were surprised*" that her child had HIV because the hospital staff wondered "*what was happening looking how things were done*". The phrase "*how things were done*" meant that the caregiver had "followed the protocol" for the child to remain HIV-negative. Hospital staff said to each other "*The lady followed the protocol for nevirapine and the child looks to be HIV positive*". She further stated that the "*child also received nevirapine soon after birth*". "*Nevirapine*" is also administered to the child immediately after birth to further ascertain that the child was protected from HIV infection that may have been transmitted during delivery. Therefore, her child could not have acquired HIV, which was an emotional situation.

Theme Two: Coping Mechanisms and Resilience

This theme examined the methods and techniques used by female caregivers to address the difficulties they encountered. The subthemes included social support systems, spirituality, involvement in the community, and adaptive coping techniques that helped caregivers continue to provide care despite their challenges.

Sub-theme Family deciding to take HIV test

In some situations, the entire family could decide to go for an HIV test after seeing that the child was frequently sick. For example, the family of Mayi Ntchisi underwent an HIV test when the child frequently became ill. Mayi Ntchisi was one of the women caregivers who were difficult to get information from however, she explained that she discovered that she had HIV when her child was getting "*sick*". Mayi Ntchisi further stated that together with her husband decided to take the child to the hospital and all of them were tested for HIV at the hospital visit, and the HIV test results were positive for all three of them. "*And when he was seen, by then we had our blood tests too for HIV*. *They found the small animal of HIV in our blood as well as the blood for him*". The phrase "*as well as the blood for him*" referred to her husband blood for HIV test. After the HIV seropositivity results, they were all commenced on ARVs and she ascertained it when she stated that "*when he was found with it, they told us to start receiving the medicines*". The term "*medicines*" refers to ARVs.

Sub-theme: Caregivers taking HIV tests before the sick child

A small number of female caregivers were diagnosed as HIV-positive when the child they were looking after had become sick and had gone to the hospital for treatment, but they were first tested for HIV before the sick child. For example, Mayi F stated that she discovered that she was HIV positive when her child was "*sick*" and she had "*gone to the hospital for an HIV test*" and she reported that she was found with "*the small animal*". Mayi F stated that when she had gone to the hospital, "*doctors*" decided to test "*her first*" for HIV and then thereafter, they "*tested the child*" tested the child'. She described that the HIV test results showed that she had the "*small animal in her blood*" and so too was her child.

Mayi Dedza, 32 years old, was a widow, HIV-positive, and on ARVs, her husband had died of HIV and AIDS. The female child was living with HIV and AIDS, was eight years old, and was on ARVs. Mayi Dedza described how she was giving ARVs to her child per day. Mayi Dedza stated that "*she gave their children in the morning ARV dose at 6 am and then she took hers too at the same time*". She described that she gave her children ARVs after the children had taken the morning "*porridge*". Mayi Dedza lamented that "*as a single parent she could not take care of the child because life in the villages was hard*".

During midmorning, she reported that "*she does cook m'gaiwa (maize) porridge where she added Nsinjiro*" *and gave her children to eat*". She also cooked available snacks, such as sweet potatoes, midmorning, whenever she had money to buy them. She also bathed her child in the morning before giving the child an ARVs. This woman's caregiver described that she cared for her child in the afternoon by giving her '*nsima'* (cooked and hardened maize porriage) with "*relish*" of the day. She explained that they bathed her child and then let her go and play with the other children. When she had finished caring for the child, she said that she went around the village looking for "*ganyu*" (*piecework*) r stayed at home. During the rainy season, she said that she had worked in other people's gardens for tender crops.

All female caregivers explained that evening activities provided a similar form of cooking food for the family as a whole. One of the caregivers, Mayi Muyeza, narrates that in the evening, "*she cooks nsima and all the children eat together from the same plate*". She uses the same "*relish*" she cooks in the morning. She also explained that in the evening she goes again to the vegetable garden to tender crops such as "*mpiru (mustard) and tomatoes*" and that "*they do sell to vendors in a wholesale manner*". She also cooks the ''*m'gaiwa*'' (maize) porridge to which she adds ''*nsinjiro''* (pounded groundnuts) hand gives her children, including those living with HIV or AIDS.

Mayi Dedza reported that she followed similar evening routines, such as bathing their children. She also described that after bathing her child and seeing that all the other children had eaten, she gave the child ARVs at 6 pm. She then described that she had prepared a sleeping place for all the children.

May F: She stated that her husband was a very good example, where men denied that they might be responsible for infecting their family with HIV. Here, family meant that she and her child lived with HIV and AIDS, respectively. She stated that such men denied responsibility, instead of blaming their wives.

> "*I said okay let it be and only God knows who brought this problem into the family. I was in a difficult period and I was hurt and I hate that period. Until when the child was born, there was no peace in my family I joined the church women's group which supported me spiritually*".

Mayi F lamented that there was "*no peace in her family*" because the child was HIV positive and that she was HIV positive as well. She stated that "*she hates that time (during pregnancy)*" and discovered that she was HIV positive because her husband traumatised her psychologically until the child was born. The husband did not want to be tested for HIV.

Sub-theme: Husband's responsibility regarding HIV and AIDS in the family

Mayi B, 31 years old, with a 9-year-old child who was HIV-positive and had received ARV treatment. However, her husband refused to undergo an HIV test and blamed her for bringing HIV into the family. Mayi B was a female caregiver who spoke very little about their husbands; however, she described her husband as "*a drunkard…My husband is like he is using the money for two families one is me and the other is the beer that he drinks and he uses a good part of the money (salary) on beer. He drinks a lot of beer and that for him to care for the family is a big problem. She decided to join people living with HIV and AIDS called Tigawane (translated as Sharing) and l got encouraged and much support*" This husband did not want his wife to be involved in this research, and later Mayi B withdrew from the study.

Theme Three: Social and structural barriers

This theme encompasses the social and structural factors that contribute to the invisibility and unrecognised nature of care provided by female caregivers. The subthemes were limited access to healthcare services, lack of financial support, inadequate social support

systems, and prevailing gender norms and expectations that marginalised and devalued caregiving roles.

She later described that "*the traditional healer*" did not "*examine*" the child very well as she put it; "*I tried very much there at the traditional healer but he could not tell me the truth about the illness of my child. I guess this is because, at the traditional healer, they don't examine the patient as it is at the hospital*". Therefore, she "*saw*" the need to go to the hospital for a proper "*examination*" of her child and for her examination too.

Sub-theme: Grandparents looking after a niece

The grandparents were Mayi Kasungu. Mayi Kasungu was an elderly woman over 70 years of age who was looking after her niece at the time of the interviews. Her husband died many years ago and lived only with her niece. "*Eee! I cannot remember nor know the years when she was born as am an old woman (she was in her late 70s or she may be 79 years old) I did not even go to school so I cannot know the years. But his wife is in the grave for 5 years now since she died*". Mayi Kasungu here was trying to recall when her niece was "*born*" but she failed. Mayi Kasungu was a good example of a rural woman who could not read and write as she confirmed that she "*did not even go to school so she could not know the years really*". She could not remember the events that led to HIV and AIDS seropositivity in her niece. The word "*years*" referred to her actual age. However, she remembered when the child was diagnosed with HIV infection.

Mayi Kasungu stated that she took the child to the Mponela AIDS Information and Testing Center (MAICC) for an HIV test, as she narrated:

> "*…And silently I whispered to her that I have come with my friend here, this child is my brother's daughter but she stays with me. And she wondered saying aa each, and I said yes, and she said eee not you? And I said no, not me off-course I have come with her to be tested and not me and she said okay. ..My friend here I have tested her for HIV and she has the HIV in her blood. Here I was worried and I said to myself, eee and where did she get this HIV this child. But we were given the paper and the lady told us to go to the hospital for the medicines that stop the small animal*".

Sub-theme: Grandparents looking after a granddaughter

Another grandparent looking after a child living with HIV and AIDS was Mayi Nsanje, who was in her early 80s. When she stated that "*this was not showing very well*" she was talking about the signs and symptoms of the child's illness and that they were not exhibiting very clearly to her. Therefore she "*sought hospital help*" so that she could know what the problem with the child was. At the hospital, she was told that "the child had the small animal in her blood". At that point, "*she remembered that the child's parents died of the same disease*". Here, the phrase "*the same disease*" refers to HIV and AIDS because the child's parents died of HIV and AIDS. "*They all died of the small animal disease*". She described that since both parents of the child died then "*the child had to be staying with her*" as a grandparent. When she used the word "*we*" she was referring to herself because that was how elderly people talk of themselves in Malawi. It was a way of self-respect, and it was in order in Malawian culture.

Theme Four: Lack of Recognition of Needs by Services

Mayi Dowa was a 36-year-old 5-year-old girl living with HIV and AIDS, who was taking ARVs. Mayi Dowa described how she was feeding her child the food supplements that she had been receiving from the hospital. However, the hospital personnel decided to stop food supplements for her child because the child had reached what she called "*a weaning body weight*". She further stated that she was powerless "*in the eyes*" of the hospital staff as she explains that "*everything was in the hands of the hospital staff*" and that "*there was nothing*" that she could do even though her child was "*still weak and looking sick*". The study team, in agreement with the study supervisor in the United Kingdom, intervened, and the hospital continued to provide all food supplements to her child because it was a matter of life and death. She stated that her "*child had gained weight from 4.1 kilograms to 8.1 kilograms*" at the time of the interviews. Mayi Dowa explained this in the following narrative: the child appeared healthy when the research team visited the caregiver during the data verification period. May Dowa was happy and the child looked happy and healthy. She explained that her "*child continued to receive food supplements and that she was very grateful to the research team*". Mayi Dowa is an example of the responsibility of caring

for a child living with HIV or AIDS.

Theme Five: Impact on Children's Well-being

This theme explored the implications of invisible and unrecognised care on the well-being of children affected by HIV/AIDS. It included sub-themes such as potential effects on children's physical health, emotional development, educational opportunities, and social integration. Mayi Lilongwe was a 40-year-old woman living with HIV but not with ARVs, who had not yet developed AIDS. Her husband died of HIV and acquired immunodeficiency syndrome (AIDS). The child was living with HIV and AIDS on ARVs, 8 years old boy. The child was HIV-negative and acquired the virus when he was six years old. "*This child was a loved boy by his father and he used to share with him his razor blades after he has shaved his beards, then l could see him shaving him and I think that is when he got the small animal because he was born free of the small animal until when he was 6 years old. I could not stop him to stop sharing the razor blades with him*".

Mayi Mpanda 3, 26 years old in a stable monogamous marriage HIV + on ARVs, husband HIV+ but not ARVs supportive. The child was a male child aged 3 years old, on ARVs. Mayi Mpanda 3 described how she discovered her HIV and AIDS statuses. Mayi Mpanda 3 stated that she discovered that she had HIV when the child was getting "*sick frequently*" and she decided to "*get help from the traditional healer first*". Mayi Mpanda 3 was the only caregiver who described that she first started the treatment of the child with a traditional healer, but she did not get the help she desired.

Sub-theme: Diagnosed HIV positive when the child became sick

The majority of female caregivers discovered that they were HIV-positive after the child they were looking for became sick and sought hospital treatment. It was mandatory in Malawi for every sick child who had been admitted to a hospital to be tested for HIV. For instance, nine of the female caregivers interviewed were diagnosed with HIV because their child became ill and the child was diagnosed first and then diagnosed. For example, Mayi Dedza discovered that she had HIV when her child "*became sick*" and she had taken her child to the hospital for the HIV test because she noted that "*the child could be very sick*". After the child was tested for HIV, her HIV test was performed simultaneously, and the results were HIV-positive. When she stated that "*we had it together*" she said that she had taken the HIV test at the same time as the child. The phrase "*the same disease*", referred to HIV and AIDS. When she stated that "*he could be wondering what he had eaten*", meant that the child did not know what his problem was for him to be sick so frequently.

> "*It's because he could be very sick and then we took him to the hospital and he could be wondering what has he eaten but he should know that it's the same disease. It was at the same time I went to have him tested for the blood test for the small animal. That was last year. We had it together*".

Another example is Mayi Mzimba, who discovered that she was HIV-positive when "*her child was sick*" and had gone to the hospital for treatment. She also stated that while at the hospital, the child was tested for HIV, and the results were HIV-positive. The hospital staff then asked her to be tested for HIV following the child's HIV seropositivity. She accepted that the HIV test results were positive. However, Mayi Mzimba stated that her husband did not want to go for an HIV test because he thought he was "*normal*" and blamed his wife for bringing HIV and AIDS into the family. She explained that he "*refused to take the HIV test*" and he had no immediate intentions to do so.

> "*I went to the hospital with the child who is 6 years old and when they had tested her and found that she was HIV positive they told me that I should also have the test for you. Then I told my husband about it and he said it is okay. But then I said to him you need to go for the HIV test as well. But he refused and told me that he would go to Mtengowanthenga hospital for the test together with my child born to you and me. And I told him that he was delaying, he needs to do it quickly so that he can start the ARVs in good time. These days with the coming of the ARVs, one needs not delay the HIV test. And he said I will go for the test but until now he has not gone for the HIV test*".

Theme Six: Empowerment and Advocacy

This theme focused on opportunities and strategies for empowering female caregivers and advocating their rights and recognition.

It had the following sub-themes: community mobilisation, policy advocacy, capacity building, and efforts to shift societal attitudes towards recognising and supporting the valuable care provided by female caregivers.

Sub-theme: Powerless husband with complex life, but empowered by the father-in-law to make decisions

Mayi Kasangadzi 4 was a 26-year-old woman living with HIV, AIDS, and ARVs in a complex polygamous marriage. She was caring for her female child, who was also living with HIV and AIDS aged 7 years. Her husband was HIV positive and on ARVs, but she believed that he was not concerned about his HIV status or the possibility that he might have infected others because he continued to marry other women. She described being "*the first wife*" but her husband has two other wives that she described that "*were below her*". She thought that a man with "*three wives*" may not be able to take care of all the needs of each wife adequately, and therefore, there are many problems associated with polygamy. She went on to plead that "*let him leave the other two wives and he should remain with me alone because of the problems that are in this house, I think that can help a lot in caring for the child*. She described feeling helpless and powerless and expressed it in the narration that follows. She tried to reach her husband during the period when they were on "*separation*" so that he could assist her with money to take care of their HIV-positive child. However, she could not reach her husband as she found out that her husband "*had changed his telephone numbers*". In response, she sought help from her father-in-law when her child was very weak and needed to go to the hospital with the child and 'the grandfather of the child", gave her K200.00 (50 pence) for "*transport*" to take the child to the hospital and obtained ARV medicines. However, "*by chance*" Mayi Kasangadzi 4 was able to track down her husband and seized the opportunity to talk to him about the problems she was facing in caring for a child with HIV and AIDS. She described her husband as not showing any "*remorse*" about passing HIV onto their child. However, when she discussed the child's condition and the problems she faced when caring for the child, her husband was '*concerned*'. He arranged for the child to be admitted to Mponela Rural Hospital. Mayi Kasangadzi 4 is a good example of living with a husband with a complex lifestyle and control. She was powerless to stop risky behaviours, and she could not do anything at all. She was empowered by her father-in-law to stand by herself to make decisions.

Sub-theme: A supportive husband and wife empowering in decision making

Mayi Machentche was 39 years old on HIV + but not on ARVs, in a monogamous stable marriage, husband HIV + and on ARVs to and supportive, child 11 years old male, on ARVs as well. May Machentche described how she checked the stock of ARVs for her children and husbands. She described that ARVs were given under "*strict rules*" to recipients to avoid the development of resistance which she called in the local language of Chichewa "*kuwopa kuti ma ARV asasiye kugwira ntchito yake being*". She stated that each recipient was taught to check the stocks and reports at each hospital during each visit. She described the checked ARV stocks for both her child and husband and reported them to the health worker at each visit. She said that she followed these rules well, including how to administer HIV and AIDS medicine maintenance doses to her children. The patients were asked how many tablets were left during each visit to the hospital. She confirmed this point when she stated that "*They asked us how many tablets are you left with at home, and we said they are there eight ooh wait a minute, it was nine and not eight tablets left*". The word "*medicines*" here refers to ARVs and not any other related medicines because it is only ARVs that are well audited. She stated. She also described that maintenance drug administration was the responsibility of each caregiver, and they all must follow the same drug dosages as she narrated that she "*gave her child the maintenance dosages of ARVs as recommended at the hospital*". She also stated that at first, her child was given pediatric ARV tablets and later switched from pediatric to adult tablets because they said that the children had gained weight that required the child to take an adult tablet. Mayi Machentche contended this when she stated, "*When I came to bring the medicines, they told me that today we will change for the child and you should be giving the child a quarter tablet in the morning and the evening half tablet*". Mayi Machentche was dedicated to ensuring that her child had taken the ATVs, and she had double responsibilities, as she was also required to look after her husband, who was on ARVs. She had to ensure that she audited the ARVs.

Discussion

The discussion of these themes and sub-themes provides a deeper understanding of the invisible and unrecognised care of female caregivers of children living with HIV and AIDS in rural Malawi.

Burdens and challenges

The burdens and challenges faced by female caregivers are multifaceted and have significant implications for their well-being. The physical demands of caregiving coupled with emotional strain can negatively impact health and well-being (Penning and Wu, 2016; Phillips et al., 2023). Financial strain adds a layer of difficulty, making it challenging for them to access necessary resources and support. Stigma and discrimination, directed towards both the caregivers and the children they care for, further compounded the burden they face (Kumar et al., 2022; Mujjuzi et al., 2021).

Coping mechanisms and resilience

Female caregivers employ various coping mechanisms and resilience strategies to navigate the challenges they encounter. Social support networks play vital roles in providing emotional, advisory, and practical assistance (Namasaba et al., 2022; Parkinson et al., 2022). Spirituality and faith are sources of strength and peace, respectively (Asa et al., 2021; Ozcan et al., 2021). Active community engagement allows caregivers to share their experiences, learn from one another, and find a sense of belonging. Adaptive coping strategies enable them to persevere and continue to provide care, despite the difficulties they face.

Social and structural barriers

Social and structural barriers contribute to the invisible and unrecognised nature of care provided by female caregivers. Limited access to healthcare services prevents them from obtaining the necessary medical support for both themselves and their children (Ward et al., 2023). The lack of financial support further exacerbates their challenges as they struggle to meet their basic needs (Gardiner et al., 2020). Inadequate social support systems, such as a lack of community-based programs or support groups, leave caregivers isolated and lack resources (Yang et al., 2022). Prevailing gender norms and expectations devalue and marginalise caregiving roles, perpetuating the invisibility of their contributions.

Impact on Children's Well-being

The invisible and unrecognised care provided by female caregivers can have a profound impact on the well-being of children with HIV/AIDS. These potential effects extend beyond physical health and encompass emotional development, educational opportunities, and social integration. Without recognition and support, children may face difficulties in accessing healthcare, experience emotional distress, have limited educational prospects, and experience social stigma and exclusion (Atanuriba et al., 2021).

Empowerment and Advocacy

Empowering female caregivers and advocating for their rights and recognition is crucial for addressing the challenges they face (Szlamka et al., 2022). Community mobilisation efforts can foster solidarity and provide a platform for collective action (Mabetha, Ojewola, et al., 2023). Policy advocacy can drive systemic changes to improve access to healthcare services and financial support (Pollack Porter et al., 2018). Capacity-building initiatives can equip caregivers with the necessary skills and knowledge to effectively navigate their roles (Leslie et al., 2020). Shifting societal attitudes towards recognising and valuing caregiving as a vital contribution is essential for breaking down barriers and supporting female caregivers.

Conclusion

This paper has presented a study aimed at developing, testing, and validating the the Share the Care Model, with a focus on addressing support services for caregivers, particularly those caring for individuals affected by HIV/AIDS. The study sought to identify and analyse the challenges faced in delivering support services to caregivers, with a particular emphasis on those caring for individuals affected by HIV/AIDS. By examining these challenges, the research aimed to gain a comprehensive understanding of the barriers and limitations that exist in current care practices. The second objective of the study was to create a platform for generating learning issues and sharing experiences among caregivers. This objective aimed to facilitate knowledge exchange and mutual learning among caregiv-

ers, enabling them to benefit from each other's experiences, insights, and best practices in caregiving for individuals affected by HIV/AIDS. The study also aimed to investigate the current provision of support services available to caregivers, specifically focusing on the context of HIV/AIDS care. This objective involved evaluating the existing support systems, identifying their strengths and weaknesses, and assessing their effectiveness in meeting the needs of caregivers and those affected by HIV/AIDS. Through this study, the researchers sought to contribute to the development and validation of the Share the Care Model, which aims to address the challenges faced by caregivers, particularly in the context of HIV/AIDS care. By analysing challenges, promoting knowledge sharing, and examining current support services, the research provides insights and recommendations for enhancing the support provided to caregivers and improving the overall care ecosystem for individuals affected by HIV/AIDS.

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