



Family Care-Giving in Mental Health: Experience of Family Caregivers of People Living With Severe Mental Illness in Rural Malawi

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**FAMILY CAREGIVING IN MENTAL HEALTH: EXPERIENCE OF FAMILY
CAREGIVERS OF PEOPLE LIVING WITH SEVERE MENTAL ILLNESS IN RURAL
MALAWI.**

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Family caregiving in mental health: experience of family caregivers of people living with severe mental illness in rural Malawi.

ABSTRACT

Malawi, like other low-income countries, has a dearth of access to mental health services and community family support programs. Care for patients with mental illness falls to families who provide care within the home. Our study sought to understand the experiences of family caregivers of patients living with severe mental illness by exploring the cultural dimensions of family caregiving practices and the effects of family caregiving on both patients and caregivers.

Design

This qualitative study was conducted using semi-structured individual interviews with 52 participants that included people living with mental illness and their family caregivers, community leaders, health care workers, and policy makers. Additionally, we conducted a week-long ethnographic observation with three families and a day long observation with six families. The interviews were translated, transcribed and analyzed inductively together with the field notes using conventional content analysis. We started with open coding of a subset of the interviews to develop a codebook, and we analyzed the codebook and field notes to develop the descriptive categories from which final themes and results were generated.

Results

Family caregivers' lived experience is marked by impoverishment, isolation, and neglect. Social support networks are splintered as a result of caregiving responsibilities and the

manifestations of patients' symptoms which leaves caregivers and people living with mental illness uncertain and hopeless about the future.

Conclusion

Family caregivers of people living with severe mental illness in rural Malawi are abandoned and trapped without hope through the experience of caregiving at home. Our findings highlight the fundamental role played by this population of caregivers as well as their vulnerability. Strategic support of this population such as the development of community mental health services and family support programs would serve to reduce the extreme isolation and the burden of caregiving.

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1. INTRODUCTION

In July 2016, while working as a mental health clinician for the government of Malawi in Neno District, I met Mambiri. Mambiri lives in the outskirts of Chikonde village in rural Malawi. She is an older woman who lives in a very small mud-built house with her 26-year-old son Mbiri who has been living with bipolar disorder for over 10 years. During our mental health outreach visit to Nsambe health center, a community volunteer told me about Mbiri, whom she said had relapsed and was being violent against his mother and the surrounding community. His mother was unable to take him to the hospital, and community members were not willing to help. It took me four hours by foot, passing through a series of dirt roads, to visit Mambiri's home at the far end of her village. Mambiri looked thin and fragile, struggling with hypertension and diabetes diagnosed two years ago at the main district hospital situated four hours away by car. Her thin body was covered with a dirty, worn out chitenje (cloth) and her visibly swollen feet were left uncovered. Looking dejected and moving slowly, Mambiri welcomed me into her small house. Upon entering the house, I saw a dark, smoke-smeared wall and some burnt pieces of wood.

"Sorry, you will sit on this tin," she said while giving me an empty tin to sit on. "As you can see on the walls, eight months ago he set this room on fire and in the process all the chairs and beddings were burned. Neighbors helped me to extinguish it before the fire spread to the whole house."¹

Mambiri's husband of thirty years left her soon after the onset of Mbiri's illness. He was fed up with Mbiri's illness and felt ashamed to have a son with mental illness. "My husband left me because of our son's illness," she said. "He used to beat us both, so he got angry and went to

¹ Mambiri's interview was conducted during the home visit on July 23, 2016, in rural Malawi.

stay away, stating that I should seek help from my relatives. Since then I have been struggling to take care of Mbiri by myself.”

Mbiri is the fourth child born in a family of seven siblings. He was a bright student and passed through primary education with flying colors. But in the fourth year of his secondary education at the age of 15, he suddenly developed his illness. Since then, Mbiri has visited different traditional healers in the surrounding communities but his condition has not improved. His last contact with the main hospital was four months ago, where he was treated as an outpatient with some medications to be taken daily at home. According to Mambiri, the medications have been helping, as evidenced by his reduced behavioral problems. However, due to a long distance to the hospital, they missed their last two appointment dates which have led to their running out of the medications. This has caused Mbiri’s behavioral problems to resurface. He is now violent and destructive at times.

“There is one hospital at the boma (trading center) that provides mental health services, and it takes almost four hours for us to get there on foot...and with the condition of the patient, we take almost the whole day and that is why he has been on and off medications for the past months,” said Mambiri.

Because of his illness, Mbiri is unable to complete basic activities of daily living, and he is unable to take care of himself. This means he relies on his mother for almost everything, such as finding food, washing clothes, and provision of water for bathing, among other things. “Because of his illness, he is just like a child. He relies on me for everything, just like a baby,” she said. Mbiri’s siblings have since all grown and left home to live on their own far away from the village.

With her husband and siblings gone, Mambiri is left to live alone with Mbiri as the sole primary caregiver in this isolated area. Worse still, in this community as in the surrounding communities, there are no community-based programs to support families who are taking care of relatives living with mental illness such as Mbiri. “I am all alone with the patient, nobody comes to give me a hand, not even any kind of assistance. I don’t have anybody to share the challenges and pain I am going through,” she said.

Shouldering the responsibility of caring for her son has led Mambiri to give up her nine-year-old business of selling tomatoes. This has left her impoverished, unable to even afford basic needs such as food, soap, and clothes. The harsh demands of being the sole caregiver do not allow her time to work in the field, to grow crops for food, and it is not uncommon for them to go to sleep at night without food. As Mambiri told me, “Because of his illness, I only spend a little time in the field so that I can have time to find what food to prepare for him and to take care of him. So, I am unable to do reasonable farming, as such we don’t grow much food to sustain us.”

This story of Mambiri and her son is one example of a family caregiving experience in a low-income country such as Malawi. It highlights the effects of severe mental illness on a primary caregiver and shows how caregivers manage their daily lives with an unpredictable trajectory of caregiving. As seen in this story, family caregiving responsibility is highly complex and demands much from the primary family caregiver, including significant sacrifices for the sake of the wellness of the care recipient. It is even more complicated in a setting where no community structures exist to support patients in care, and where poverty and stigma are prominent. Nonetheless, families find their own means of managing this responsibility amongst the competing demands of daily life. Mambiri’s case left me with the desire to answer the

broader questions regarding family caregiving: how can family caregiving in mental health be described in this setting? What main functions of caregiving are involved in this family-based caregiving? What effects does caregiving have on the primary caregiver and the family unit? How does culture influence decisions around mental illness and caregiving practices?

Inspired by Mambiri and Mbiri's experience, I wanted to answer these questions by gaining an in-depth understanding of what family caregiving looks like through the eyes of the family caregivers and patients themselves, and by spending time with them and observing their daily caregiving practices. This is why my thesis uses both qualitative, in-depth interviews and ethnographic observations to create a rich description of family caregiving in a setting of prominent poverty and stigma, and lack of mental health services and community-based family support programs.

In what follows, I will first describe health services development in pre-colonial, colonial and post-colonial Malawi, followed by the burden of mental illness around the world. I will then describe the social construction of mental health care, and explore family caregiving in mental health literature. Finally, I will discuss mental illness and culture, in the context of global health, and then in rural Malawi.

2. BACKGROUND

2.1. History: Colonial Health Service and Mental Health Services in Malawi

Mental health services in Malawi, like many other low-income countries, are poorly developed compared to physical health services, and they are mostly centralized to institutional care with minimal community involvement, leaving the majority of people in need of care without access.¹ Despite mental disorders being a significant contributor to the burden of illness worldwide,² the majority of low-income countries including Malawi still dedicate less than 1% of their total health budget towards mental health services.³ There are several questions that need to be answered. Why are mental health services in Malawi not as developed as other health services? Why is there still low government commitment to improving mental health services despite mental disorders being a significant contributor to the disease burden? History perhaps can help us to understand the root causes of this indifference and inequity. This section will look at health service development during the pre-colonial, colonial, and post-colonial periods in relation to the attention that mental health services have been given during the same periods in Malawi.

2.1.1. Pre-colonial and colonial medical services

Hokkanen pointed out the significance of Christian missionaries in establishing early health services in pre-colonial Malawi, and the way they remained the main providers of health services during the colonial period until after the First World War when the colonial government started making some efforts to invest in health. This is largely attributed to David Livingstone, a Scottish explorer and a missionary who was a key figure in the establishment of missionary medicine in Africa. His exploration of Africa "opened" large parts of Africa, as he "exposed the

‘wounded’ of the slave trade” and the “need for the ‘wounded’ to be healed.”⁴ Livingstone’s 1859 arrival in Malawi paved the way for more European missionaries, who built missions that also provided medical services such as the Livingstonia mission of the Free Church of Scotland in 1875, Blantyre Mission of the Church of Scotland in 1876 and the English Anglican Universities’ Mission to Central Africa (UMCA) in 1882.⁵

The subsequent waves of colonizing Europeans saw the British slowly taking control of Malawi, and in 1891 most of Malawi was formed into the British Central African Protectorate (which later was named Nyasaland) with Harry Johnston as the first commissioner for the colonial government.⁶ Harry Johnson’s administration ran under a very limited budget of around \$250 for the entire medical service, as a result they employed a very small number of doctors who, as Hokkanen observed, were most concerned with treating the small number of Europeans and their African workers, leaving the majority of the indigenous population not exposed to Western biomedicine until the Second World War.⁵ This supports the assertion that the early development of colonial medicine was only intended to protect the colonialists against the local diseases, and they were not concerned with the health of the indigenous population.⁷ In 1895, a new health department under the colonial government was established at Zomba by Woodsworth Poole, who was the first permanent medical officer. Poole expanded the health services after the First World War to most parts of southern Malawi.⁸ However, as Colin Baker observed, the expansion of these services was still not for the greater good of the indigenous population, but rather for the (white) government officials and their (African) workers. No wonder these services were only stationed where government officials were situated.⁹ Nonetheless, mission medicine remained the primary source of Western medicine to the majority of the rural population and it continued to expand further with the establishment of St. Luke as the missions’ major hospital in

1890, UMCA hospital in Likoma as a second largest mission hospital, and Central Hospital in the north.⁵

Although mission medical services expanded across Malawi,⁹ there was no effort to provide services to people living with severe mental illness (today called psychotic disorders, such as schizophrenia). The colonial administration took no responsibility for caring for them, and even mission hospitals were refusing to admit such people who were regarded as ‘mad’.¹⁰ By the time the British Central African Protectorate (now Malawi) was named Nyasaland in 1907, no care was available for people living with severe mental illness,¹¹ a lot of whom were just left wondering in the communities and others were just incarcerated in prisons. The missionaries however pressured the government to take the responsibility which led in 1910 to the establishment of Zomba Lunatic Asylum, an annex to the Central Prison, under the administration of the Department of Prisons until 1951.¹² But as Megan Vaughan observed, the asylum was not established to provide care for the mentally ill patients; rather, it was just meant to contain the people who had mental illness from the rest of the prisoners.⁴ Between the First World War and Second World War, health services continued to expand with the colonial government building hospitals and dispensaries across the country,¹³ but their focus was on physical illnesses, leaving Zomba Lunatic Asylum as the only available service for people living with mental illness.

In 1953, the colonial government built a new mental hospital called Zomba Mental Hospital, which marked a new era in the history of mental health services in Malawi, as psychotropic drugs and electroconvulsive therapy were available for treatment of patients with mental illness.^{12,14} By the time the Federation of Rhodesia and Nyasaland was established in 1958, the mental hospital had over 200 patients, and it was the only hospital available for people

living with mental illness.¹⁰ Years later saw the continued expansion of physical illness focused mission medicine with the establishment of more hospitals and dispensaries across the country.¹³ Meanwhile, Zomba Mental Hospital (ZMH) remained the only hospital for mentally ill patients in Malawi.

2.1.2. Postcolonial medicine and mental health

In 1958, Dr. Hasting Banda was called back to Malawi from Ghana where he was practicing as a medical doctor to lead the Nyasaland African Congress, a major political party founded by Malawians which was renamed Malawi Congress Party (MCP) in 1959.¹⁵ The MCP won the first general elections to the legislative council in 1961 and, the following year, the British agreed to make Malawi independent, which subsequently was followed by dissolution of The Federation of Rhodesia and Nyasaland in 1963 and Malawi became independent on 6 July 1964.^{16,15,8}

During the Federation of Rhodesia and Nyasaland, Malawi's public health service was financed through periodic funding from the federal office.¹⁷ However, dissolution of the federation meant that the government had to finance health and other public services on its own which caused great economic problems.¹⁷ Struggling to find means of financing health services, Dr. Banda's government introduced health user fees soon after Malawi's independence in 1964.¹³ It was the first time people in Malawi had to pay for health services, since medical services were free during the colonial period. This change did not go over well with the public and even some ministers resigned in protest, which forced Dr. Banda to abandon the user fee and make the services free to all once again.⁸ That decision marked a turning point in the history of

the country as since then Malawi has had free health services despite growing pressures from neo-liberalists to privatize health services.

Desperate to find means of financing health and other public services, Dr. Banda's government, as many other resource-limited countries, resorted to getting loans from the World Bank and International Monetary Funds (IMF).^{7,17} Additionally, he continued to rely on the agriculture-based economy inherited from the colonials¹⁵ and created special loans for agriculture investment to Malawians.^{17,15} During this time, health services started to slowly expand with more hospitals and dispensaries opening in rural areas, and the number of medical professionals also increased. For example, the number of medical doctors increased from three in 1964 to 12 in 1974 and recurrent expenditure on medical services also increased from £219,000 to £505,000 during the same time period.⁸ However, these modest developments in health slowed down following the International Monetary Fund (IMF) and World Bank's introduction of structural adjustment programs, which were the fiscal control measures attached to the loans given to countries.^{18,7} These conditions restricted the Malawi government's expenditure on health and other social services in favor of private sector investments,^{13,7} which slowed government efforts to continue the expansion of health services. However, missionary medical services continued to slowly expand with Catholic and Seventh Day Adventist missionaries opening up hospitals and mission schools to train nurses and auxiliary medical assistants.¹⁹ Despite this slow progress in the health sector overall and modest expansion of health services, mental health services remained centralized at Zomba Mental Hospital, which made the services hardly accessible to the majority of patients in need.¹²

In the decades that followed, the government launched additional initiatives to train more health professionals with the establishment of Kamuzu Nursing College in 1979 and the College

of Medicine in 1991 to train nurses and doctors respectively. Other allied health professionals were continually trained at Lilongwe School of Health Sciences and Adventist Malamulo School of Health Sciences.⁹ Modern government hospitals such as Mzuzu Central Hospital were also built. Malawi remained a free health care country.

Regarding the expansion of formal mental health services in the health sector, St. John of God Hospitaller Services, a mission Catholic institution, established a mental health hospital in north Malawi in 1998. They also established a St. John of God College of Health Sciences to train psychosocial counselors, psychiatric nurses, and mental health clinicians.²⁰ At the time of this writing, Zomba Mental Hospital and Saint John of God Hospital remain the main psychiatric facilities.

This early history suggests that mental health services have a rooted background of being neglected during the time that formal health services were first developed in Malawi. Decades later, we are still seeing the same trend of a very neglected, underdeveloped, and inaccessible service where over 80% of the patients in need of care like Mbiri are still failing to access the service²¹ despite substantial progress in infectious disease services such as HIV care. This history should urge us to reverse the current status quo by putting greater effort towards mental health care while continuing to build other health services such as HIV, malaria, and malnutrition care.

2.2. The Burden of Mental Illness

According to the World Health Organization, mental disorders account for 13% of the total global burden of diseases worldwide. Depression alone is currently the third leading cause of global disease burden and it is predicted that it will be the leading cause of global burden of

disease by 2030.² This is calculated based on the sum of years of potential life lost due to premature mortality and the years of productive life lost due to disability. Calculating for the disability component of the burden of disease, mental illness in low and middle-income countries accounts for 25.3% and 33.5% of all years lived with a disability (YLD), respectively.² Vigo and Thornicroft argue that the global burden of disease as reported by WHO underestimates the true effect of mental disorders on the population. They noted that there has been a significant increase in the burden of mental disorders by 37.6% from 1990 to 2010 which is accounting for 7.4% of disability-adjusted life years (DALY), and 22.9% of all years lived with disability. Therefore, based on their calculations, the new estimate of the burden associated with mental illness is actually 32.4%. Perhaps these figures may also be an underestimate of the true burden of mental disorders due to lack of data especially in low-income countries where over 75% of the people living with mental illness do not access services when in need.²² Nonetheless, these figures place mental disorders as a significant contributor to suffering worldwide which requires urgent attention.

According to the World Health Organization,²³ three-quarters of the total burden of mental illness lies in low and middle-income countries. Malawi is an example of a low-income country where the prevalence of mental illness is 15.03%. Mental and substance use disorders are the main contributors to the burden, accounting for 6% of total DALYs and 29% of total YLDs.²⁴ Mental health services are mostly centralized in the urban setting with minimal involvement of the peripheral health facilities making the services inaccessible to the majority of the patients in need.³ Other social factors such as cultural beliefs, poverty, and stigma also significantly contribute to this disease burden which Arthur Kleinman, Veena Das, and Margaret Locke, referred to as “social suffering,” as their influence causes significant suffering and

discomfort to both the families and patients.²⁵

Despite the documented high levels of the burden of mental illness, countries continue to spend less on mental health worldwide. This is particularly true in low and middle-income countries where expenditure on mental health is less than 1% of their total health budget and more than 60% of these small budgets are spent on running mental hospitals leaving almost nothing available for implementation of community mental health services.²⁶ This has resulted in the centralization of mental health services with almost nonexistent community mental services causing a huge treatment gap and leaving families to shoulder all the responsibilities of care.³ It is not surprising that studies elsewhere have shown a very significant high level of stress and burnout of family caregivers of patients with mental illness.²⁷

The World Health Organization's slogan "no health without mental health" from the 2004 Mental Health Report insists that mental health services must be part of physical health care, refuting the distinction between care for the mind and care for the body. This was as a result of the documented evidence of the interaction between mental and physical illness: on one hand, mental illness puts people at risk of developing some infectious diseases such as TB and other non-infectious diseases, and, on the other hand, many physical diseases such as malaria and HIV/AIDS increase the risk of developing mental disorders.²⁸ Therefore, the more mental health is ignored, the more we are putting people at risk of physical suffering, which make it even harder to achieve overall physical health. In short, the fight against physical illness cannot be won if mental health care is ignored. To reduce this mental health burden, countries and development partners need to show political will and commitment to allocate the necessary resources and provide leadership towards building effective mental health programs in integration with other services. In low and middle-income countries, efforts should be made to

understand the cultural definitions of mental illness and its informal caregiving practices to design and implement culturally acceptable community mental health services with the involvement of the service users—family caregivers and people with lived experience of illness themselves.

2.3. Social Construction of Mental Health Care: Historical Perspective

Globally, mental health care has evolved over the years from institution-based care to efforts at community-based care.²⁹ This transition has been imperfect in all global contexts. Institutionalization of mental health care dates to the late 18th century and the beginning of 19th century with the establishment of asylums across Europe and its colonial outposts.^{11,30} These asylums were established to keep people with mental illness confined to one place as a way of getting them out of the community. By this time, people living with severe mental illness were subjected to all sorts of inhumane treatment, being kept in chains at home and some even forced out of their communities into the streets or forests.^{31,30} Some endured traditional practices of beatings, starvation, and blood-letting in order to keep them under control and to cast the evil spirits out.³⁰ Critics argue that asylums were not established for provision of treatment; rather, they were for confinement and punishment for people with mental illness as evidenced by the conditions inside asylums where people were kept in windowless dungeons, on a cold floor, chained to the beds and were constantly beaten up which was similar to the conditions out in the communities without care.³²

The abysmally bad asylum conditions led to the rise of the humane care movement which was championed by three humanitarian reformers: Dr. Philippe Pinel in France; William Tuke in England; and Benjamin Rush in the United States, who advocated for provision of “moral

treatment”—a compassionate care for people suffering from mental illness. This moral treatment theory was used in different developed countries which led to the establishment of moral treatment asylums and hospitals.³⁰ Despite the moral treatment movement, some argue that conditions in many asylums did not change, in fact, they deteriorated due to underfunding and overcrowding of these institutions.¹¹ Civil rights lawyers and consumer advocates took a more active stance against state mental hospitals and their administrations to give civil rights to patients and to improve the living conditions in the institutions. This led to the birth of a deinstitutionalization movement—a move to shift mental health care from hospital-based to community-based services.³³ Advocates for community-based care argued that institutionalized care was a violation of patient’s human rights, where so often patients are socially isolated, lose their independence and responsibilities, making them struggle to cope with life outside the institution.³⁴ Backed by the World Health Organization, the community-based care movement gained ground which was followed by a lot of developed countries reducing bed capacity of mental hospitals and even closing many mental health institutions.^{33,27}

Deinstitutionalization, the movement from hospital-based care to community-based care, can be described as a social construction of reality that has defined the delivery of mental health care worldwide. As Peter Berger and Thomas Luckmann referred to, once this idea was legitimized and backed by institutional bodies like the World Health Organization, it has become a guiding blueprint of practice worldwide and hard to change.³⁵ This shift of care has also resulted in a shift of mental health care responsibilities into the hands of the families in the communities which has resulted in (perhaps unanticipated) physical, psychological, social, and financial burdens on those families.^{27,31}

Sheth and others also argued that deinstitutionalization to community-based mental health care has failed to live up to its intended goal. Patients have been deserted from the mental institutions into the communities where there are no adequate services to manage them, resulting in patients being abandoned to roam the streets homeless, starving and begging, and incarcerated in jails and subjected to physical, verbal, and sexual abuses. They also argue that compared to institutional care, delivering community mental health care is not as cheap as what proponents said it would be, but it is even more expensive.³³ Perhaps this shows how deinstitutionalization, a social construction of mental health care, with legitimization by the WHO, has resulted in what Melton referred to as “unintended consequence” of social suffering of patients with mental illness as Seth observed.³⁶ Sheth and friends have suggested that perhaps the best solution to mental health care should not be to completely abandon hospital care but rather strengthen them with more skilled staff as some patients, particularly those with higher levels of need, and agitation may still require admissions from time to time.³³

Looking at how mental health services have developed over the years and the arguments against institutionalization and deinstitutionalization, community mental health looks to be the ideal way of delivering mental health services. It improves access to the services and allows patients to recover right there in the communities among family members, which in turn may reduce stigma and promote social inclusion.¹² It must be said that the “structures” that were set as policies for the establishment of institutional care of mental illness has resulted in a form of violence against people with mental illness. Patients are even stigmatized by general health providers when attending a general primary care clinic because they are seen as a different group of people with special illnesses requiring special “mental” care.³⁷ This is the “structural violence” against patients with mental illness which has caused them to be isolated, abandoned,

and are not able to easily access even basic health services for other conditions due to stigma.³⁸

Although countries are still advocating for the integration of mental health services into primary care, resistance is still prominent in many health systems.

When talking about community-based mental health care, we have also to know that the key providers of the service are the families.³⁹ Families are the ones who provide primary care to these patients; as such, there is a need to involve them as partners in care. Studies done elsewhere have shown that the involvement of patients and caregiver family members yields a good result by improving both the patient outcome and family caregiver's outcome.⁴⁰ Therefore, community-based services should be designed to help the service users, to enhance acceptance of the services, and promote user satisfaction which could be very effective to improve the mental health of both the patients and their family caregivers. However, institutional care should not be completely abandoned at the expense of community care, as some patients still require institutional care support to be stabilized for easier reintegration into their communities.

The lessons and ideas learned from this mental health care history should guide us towards building an effective mental health care system that is culturally sensitive, especially in developing countries like Malawi where culture and stigma greatly influence mental health care. In this case, there is a need to first understand the culture of community caregiving before implementing such programs.

2.4. Mental Health Services in Malawi

Mambiri's story is a reflection of what the majority of families are going through in Malawi and other low and middle-income countries, where mental health services are not well developed and where no community programs to support families in caregiving exist.³ Mambiri

described the challenges of seeking formal mental health services in this setting and the alternative measures of care they use to get help:

- From the onset of his illness, we have been visiting traditional healers in this village who have been giving us some medications for his illness but there has not been much improvement. There is one hospital at the boma (trading center) that provides mental health services, and it takes almost four hours for us to get there on foot...and with the condition of the patient we take almost the whole day and that is why he has been on and off medications for the past months.
- There are no programs in this village that support these kinds of people (mentally ill patients); as a result, all the responsibilities lie in the hands of the family providers.

This illustrates the huge mental health treatment gap that currently exists in Malawi. It is discouraging to note that years after the discovery of modern mental health medications, still a majority of patients are not able to access care or medications that can help them. Perhaps the specific history of mental health services in Malawi is worth reviewing again. Wilkinson, described how mental health services developed in Malawi from a service that began in 1910 by the colonial government with the establishment of the Zomba Lunatic Asylum in Zomba Central Prison. This was in response to a number of prisoners who were labeled as insane and who were very difficult to manage. So, a move was made to separate these individuals from the rest of the inmates thereby creating an asylum.⁵ The asylum continued to expand because of increased recognition of the needs of mental health patients, and in 1943, the new annex was created for the quieter patients—patients who were isolating themselves and not aggressive in the prison. As Jock McCulloch noted that the asylums were created for custodial care rather than treatment as patients remained in the prison system and it was not a surprise that Zomba Lunatic asylum was

under the prison authority until 1951^{5,12}. In 1953, the new mental hospital was built and came under the control of the medical department. Although it was short-staffed, it marked a very significant milestone in mental health care, as drugs were made available to treat these patients which also included Electroconvulsive Therapy (ECT).^{10,5} The hospital was soon overcrowded as it was the only institution providing mental health services, and in 1991, Dr. Wilkinson a senior government psychiatrist working as the head of the Zomba Mental Hospital was involved in a task force to decentralize mental health care to the communities.¹² This movement as Wilkinson said was to improve access to mental health services to the rural people and to help patients recover in their communities where social integration could be easy and stigma could be reduced. This model was designed to involve psychiatric nurses working in the district hospitals to go out to peripheral health facilities and offer mental health services. These Psychiatric nurses were trained at Zomba School of Hygiene, the program that was established in 1989 by the government of Malawi to improve the gap in mental health professionals. The pilot study in Zomba was successful which saw a lot of satellite clinics being established. This model was scaled up to many districts by the end of 1992 and according to Wilkinson, it resulted in a significant reduction in patients admission at Zomba mental hospital.¹² Currently, mental health service delivery to rural populations follows this model where nurses or clinicians operate from district hospitals and conduct outreach services in primary health care settings.

Looking back on the history of mental health service development in Malawi, a lot has happened that is very positive. The effort to expand mental health services through the use of nurses to deliver mental health services in rural areas is one very good step to improve access to mental health services as Wilkinson pointed out. However, this system still leaves a lot to be desired. For example, it does not address the need to build community mental health structures

which could be sustainable. It lacks a component of involving the community members—end users themselves, which overlooks the importance of community collaboration in mental health care. Additionally, this system does not promote integration with other services, treating mental illness as a separate condition which bypasses the theory of holistic approach of care which involves treating both physical and mental illness together. In short, the continual use of this system will continue putting mental health and physical care in parallel realms of care.

It is unfortunate that decades later, Zomba Mental Hospital remains the main mental health referral hospital in Malawi. Further to that, it consumes almost the entire 1% of the total government health budget dedicated to mental health services, leaving almost no funds to build community mental health services. Much as we should not abandon institutional care, but community mental health care remains the key to improving access to people such as Mambiri's son Mbiri and the majority of others who are currently struggling without care. Developing such services requires us to understand caregiving at the community/family level. Understanding the caregiving practices at patients' homes such as Mambiri's and the surrounding community will help inform the design of a culturally acceptable system of community mental health. This thesis aims to generate knowledge to inform community mental health design.

2.5. Family Caregiving in Mental Health

Family members who are responsible for attending to the daily needs of another family member are referred to as family caregivers.³¹ They are responsible for the short term and long term provision of physical, emotional, social and financial support of another person who due to illness or injury is unable to care for him/herself.⁴¹ It is estimated that one in four families currently have a member with mental or behavioral disorders and that family members are the

primary care providers for people living with mental illness worldwide.⁴² These care responsibilities in mental health have further increased with deinstitutionalization of mental health—the movement of mental health care from institution-based to community-based care which has seen patients being cared for in their homes instead of the institutions.^{43,31} The result of this shift in care as several studies indicated, has caused a significant physical, emotional, financial and social burden to the families, and it is even more challenging where no family support programs are available.^{44,45} Caregiving in mental health is further complicated due to its unpredictable trajectory which causes results that are uncertain to the families.⁴⁵ No wonder WHO described the extent of the burden of mental illness as very significant on family members but difficult to assess and quantify.⁴² As Arthur Kleinman described, “Caregiving is not easy. It consumes time, energy, and financial resources. It sucks out strength and determination. It turns simple ideas of efficacy and hope into big question marks. It can amplify anguish and desperation. It can divide the self. It can bring out family conflicts. It can separate out those who care from those who can’t or won’t handle it. It is very difficult.”⁴⁶

Recognizing the harms and challenges that families are facing in mental health and appreciating the role they play has highlighted the need for formal mental health systems to work together with the users—families and patients as partners in mental health care—during both the design and implementation of community-based services. As Beardsley and Gladstone stressed, the best way to develop comprehensive mental health care is to develop a partnership with families while moving away from the model of expert and patient.⁴⁵ Studies elsewhere where this partnership is working has shown to significantly improve not only the patient’s mental health but also the caregiver’s wellbeing.⁴⁰ Involvement of users has worked well in developed countries where the majority of users are involved in mental health care. However, in developing

countries like Malawi, this remains a challenge as only less than 30% of users are involved in mental health care systems.²³

To form this partnership with families and mental health service providers in developing countries requires an insight into the cultural definition of family caregiving and its components. This can be done by exploring family caregivers' experiences in this resource-limited setting to help in designing community and family-based mental health care.

2.6. Mental Illness and Culture

Mambiri and her son's efforts to seek care is an example of the influence of culture on mental health on people worldwide. From the onset of Mbiri's illness, his family sought care from traditional healers because of their beliefs about the cause of the illness.

He was a very bright student and it was very strange how his illness started. That made us believe that he was bewitched by people who did not want to see him succeed. That is why we first consulted traditional healers to show us who has done that and to reverse his illness.

The meanings attached to explain mental illness in society have real consequences in terms of whether people are motivated to seek treatment or not. It also influences how they cope with their symptoms, where they go to seek help and how well they fare in treatment.⁴⁷

Historically mental illness has been explained in a religious or spiritual context where a person may be seen as being possessed by the evil spirit or made to behave in that way as a form of punishment for doing a wrong thing.³¹ Others are believed to be cursed or bewitched by their enemies.⁴⁸ Medical knowledge that mental illness is caused by a permanent brain condition in many settings is more stigmatizing to the patients and their families, making them want to hide

their illness and subsequently not access mental health services available resulting in continuous suffering.^{39,3} Stigma also affects people's self-esteem and diminishes their opportunities to access social services or even employment; they do not participate and compete equally for the limited social resources extant in their communities. Families' social relationships are also affected by stigma forcing them to live in isolation.⁴⁷ These are all dimensions of social suffering that people with mental illness face which, as Arthur Kleinman said, originate from the cultural or institutional social influences in a society.³⁸

Culture influence of health seeking behavior also causes families to seek other forms of care in their communities. For spiritual beliefs, religious leaders are often consulted to help cast the evil spirits out and when a curse is believed to be the cause, traditional healers are often visited.³¹ In Malawi, several studies have shown that traditional healers are the first point of care to the majority of people living with mental illness.²⁰ These traditional healers use culture-specific practices such as Vimbusa—where a patient dances to musical tunes, and herbs are used. This has been seen as a form of group and family therapy.⁴⁹

Health policymakers, be the medical directors, managers of private institutions, or health care financing administrators, have their own culture governing their values, attitudes, and assumptions. These are the people who shape how social services are delivered to the people and when designing policies, they look at the broader element of improving access to care, not the varied circumstances facing beneficiaries and families. "Their perspective is very different from that of family caregivers who are concerned by the needs and preferences of individuals in the context of the family."⁵⁰ Based on this, there has been a growing interest to involve mental health users-family and communities to design and implement mental health services worldwide.²⁶

Our culture determines our morals, beliefs, customs and behavior. As these are mostly

unconscious, we tend to think of them as universal, and therefore to expect others to fit our expectations. Therefore, the design of programs like community mental health services needs understanding that different communities and even different social classes have different cultures with their own expectations and values. Therefore, there is the need to understand the culture of the beneficiaries and families, and to involve them in the design and implementation of the services.

Part 2: ENTANGLED IN CAREGIVING: EXPERIENCE OF FAMILY CAREGIVERS OF PEOPLE LIVING WITH SEVERE MENTAL ILLNESS IN RURAL MALAWI

ABSTRACT

Malawi, like other low-income countries, has a dearth of access to mental health services and community family support programs. Care for patients with mental illness falls to families who provide care within the home. Our study sought to understand the experiences of family caregivers of patients living with severe mental illness by exploring the cultural dimensions of family caregiving practices and the effects of family caregiving on both patients and caregivers.

Design

This qualitative study was conducted using semi-structured individual interviews with 34 participants, including people living with mental illness and their family caregivers. The interviews were translated and transcribed and analyzed inductively using conventional content analysis. We started with open coding of a subset of the interviews to develop a codebook from which we developed our descriptive categories to come up with the final themes for the results.

Results

Family caregivers' lived experience is marked by impoverishment, isolation, and neglect. Social support networks are splintered as a result of caregiving responsibilities and the manifestations of patients' symptoms which leaves caregivers and people living with mental illness uncertain and hopeless about the future.

Conclusion

Family caregivers of people living with severe mental illness in rural Malawi are abandoned and trapped without hope through the experience of caregiving at home. Our findings highlight the fundamental role played by this population of caregivers as well as their vulnerability. Strategic support of this population such as the development of community mental health services and family support programs would serve to reduce the extreme isolation and the burden of caregiving.

INTRODUCTION

Severe mental illness impairs people's emotional, cognitive and physical competencies which leaves them unable to live independently and take care of themselves and their significant others for long periods of time.⁴⁴ As such, they need a day to day support from people around them, which traditionally are family members.⁵¹ Since the 1950's when deinstitutionalization of mental health care—the approach to treat patients in their communities rather than in long term hospitals started to take root, there has been an increasing push of caregiving responsibilities into the hands of family members,³¹ which several studies globally have shown has caused significant stress.^{52,53}

Several studies examining the impact of deinstitutionalization's shift in caregiving responsibility, have demonstrated that caregiving has significant impacts on families' physical, psychological and social health/wellbeing.^{54,55} For instance, Yip in China,⁵⁶ Tanveer and Rushsana in Pakistan,⁵⁷ and Magliano et al. in Europe⁵⁸ found a significant negative burden associated with family caregiving. Elsewhere in Africa, significantly high levels of psychological and social burdens associated with family caregiving in mental health have also been reported.²⁷

In Malawi, like many other Low and Middle Income Countries (LMIC), a weak mental health care infrastructure has left over 75 percent of people suffering from mental disorders without access to treatment²² which means the care responsibilities of the people living with mental illness lies exclusively in the hands of family members. Just like other LMIC, family support groups or family education programs do not exist in Malawi.^{14,26} This makes families as a stand-alone structure in mental health care.

Little is known as to how the lack of both formal mental health care and family-based programming in Malawi shapes the family caregiving practices, and how families manage their

daily lives. This study aims to gain an understanding of what family caregiving looks like through the eyes of the caregivers and patients themselves by exploring their cultural caregiving practices and the caregiving effects on people living with mental illness and family caregivers.

METHODS

Study Design

This qualitative study used conventional content analysis. This approach was ideal for the study because it allowed us to describe phenomena about which little is currently known.⁵⁹ By using individual in-depth interviews, this study permitted us to gain rich, descriptive information about the lived experiences of patients and their primary caregivers, and to gain a fuller understanding of family caregiving in mental health.

Study site

The study was conducted in Neno district, Malawi. Malawi is a small country located on the south-east of the continent of Africa. Malawi has a population of over 16 million with about approximately 72% living below the national poverty line. HIV prevalence remains high at 10%; likewise, maternal and child mortality are high.⁶⁰ The burden of mental illness is estimated at 15%, accounting for 6% of total Disability Adjusted Life Years (DALY) and 29% of total Years Lived with Disability (YLD).²⁴ The total expenditure on health as a gross domestic product per capita is 6.24%, and mental health expenditure is 1% of the total budget.⁶¹

Neno is a very rural and impoverished district situated in the south-west of Malawi, 145 km away from the nearest commercial city (Blantyre). It has a population of approximately 158,000,⁶⁰ the majority of whom are subsistence farmers of maize. Neno is made up of different

tribes and the local language is Chichewa. The district is only accessible via a muddy road which is largely impassable during the rainy season.

Health care is provided in this district by 14 health facilities, a District Hospital, a community hospital, and 12 health centers, 4 of which are private and the rest public. Mental health and non-communicable diseases services are primarily centralized at the District Hospital, with minimal involvement of peripheral health centers. The District Hospital employs one mental health clinician and one psychiatric nurse. Together they are responsible for the provision of outpatient services to patients seeking mental health care at the hospital. The clinician and psychiatric nurse also offer acute treatment and offer referrals for the most agitated/aggressive patients to a tertiary mental hospital in the capital. The Lisungwi Community Hospital is a rural village hospital. Mental health services are offered by the general clinicians and nurses who have undergone a week-long basic mental health training on how to identify mental illness, initiate first aid treatment and make appropriate referrals.

Sampling and Recruitment

We used a purposive sampling of selecting participants for this qualitative study. The aim was to maximize information-rich cases, as well as to represent the diversity of the population in this setting.⁶² We sampled individuals both from the district and the community hospitals, and they were from a variety of villages.

Inclusion criteria for people living with mental illness were: 18 years of age and older; written informed consent; and a diagnosis of schizophrenia, schizoaffective disorder, and/ or bipolar disorder. For caregivers, they were included if they were 18 years of age and older, and signed the written consent form.

The patient group was comprised of 17 patients diagnosed with schizophrenia, severe bipolar disorder and schizoaffective disorder who had a record at the Neno district hospital and Lisungwi community hospitals. The family caregiver group was comprised of 17 family caregivers of people living with severe mental illness as identified by the patients.

People living with mental illness and the family caregivers were identified through Neno district and Lisungwi mental health clinic records according to their diagnoses of inclusion. We mobilized Community Health Workers (CHWs) to reach out to the potential participant at home if he/she was willing to participate in the study. After the consent process, patients were asked for permission for the researcher to contact their family caregivers. With the patients' permission, family caregivers as identified by the patients were contacted by the researcher for their participation.

Data Collection

This study used semi-structured individual interviews with both the patients and family caregivers which allowed the interviewer to use an outline of questions with the flexibility to generate a systematic data collection for each respondent.⁶²

Individual interviews took place in Chichewa language and were audio recorded with permission from the interviewees. The interviews were conducted separately for the caregiver and the patient, in a private space within their respective homes during the same home visit.

Two guides were devised for each population and comprised of open-ended questions which were supplemented with follow-up questions and probes tailored to individuals' responses to each question. The interview guides for both interviews covered the following topics: (1) the onset of the illness and the pathway to seeking care, (2) the journey of caregiving from the onset

of the illness, day to day living experience, (3) interaction within and outside family, (4) the challenges and the opportunities they face, (5) their specific needs. Each interview lasted approximately 60 minutes in duration.

Data Analysis

Data were analyzed using a content analytic approach. Individual interviews were transcribed and directly translated into English by the research assistant. Transcripts were continuously reviewed in order to ensure accuracy. From the transcribed interviews, we open coded a subset of interviews in order to develop an initial codebook, which was piloted and revised. With the support of Dedoose version 8.2 qualitative software, the entire dataset was direct coded using the resultant codebook. The coded data were inductively examined to derive a set of the initial set of themes which represented participants' experiences of family caregiving. Initial themes were named and describe to develop an initial set of descriptive categories. These categories were then reviewed and revised to form a final set of descriptive categories that were illustrated using excerpts from the data.

Ethical Statement

Approval to carry out the qualitative research was obtained from the Human Subjects Division of Harvard University, and the Malawi National Council for Science and Technology. Participants provided consent for the qualitative interviews and the observations as part of the consent process for this study. Consent was re-confirmed verbally as part of recruitment for the qualitative study.

Table 1. Demographic characteristics for caregivers of patients with mental illness, (n=17)

Characteristic		n (%)
Gender	Female	15 (88 %)
	Male	2 (12 %)
Age	60 -79	8 (47 %)
	40 – 59	6 (35 %)
	20 – 39	3 (18 %)
Current guardian	Mother	10 (59 %)
	Aunt	3 (15 %)
	Sister	1 (6 %)
	Brother	1 (6 %)
	Spouse/wife	1 (6 %)
	Daughter	1 (6 %)
Number in a household	Caregiver and patient	8 (47%)
	Caregiver, patient and 1 other person	6 (35%)
	Caregiver, patient and >1 others	3 (18%)
House type	Mud built wall	13 (77%)
	Bricks wall	4 (2 %)
	Grass thatched roof	13 (77 %)
	Iron sheets roof	4 (23 %)
Occupation	Employed	0 (0%)
	Unemployed	15 (88 %)
	Business	2 (12 %)
Source of water	Borehole	5 (29 %)
	Well	3 (18 %)
	Spring	8 (47 %)
	Communal Tap	1 (6 %)

Table 2. Demographic characteristics for people with mental illness, (n=17)

Characteristic		n (%)
Gender	Female	11 (35 %)
	Male	6 (65 %)
Age	60 – 79	1 (6 %)
	40 – 59	3 (18 %)
	20 – 39	13 (77 %)

RESULTS

Participant Characteristics

Our family caregiver population was comprised of mostly women, and nearly half of them were aged above 60 years. Almost all of them were subsistence farmers of maize, and none was employed. The type of housing of most of our caregiver population was grass thatched mud-built houses, and the common source of water was natural springs. The patient population was comprised of mostly men aged between 20 to 40 years.

Descriptive Categories

Family caregivers of people living with severe mental illness in Malawi are abandoned and stuck without hope in the caregiving role. The following themes describe the embedded nature of loss and abandonment that family caregivers experience in rural Malawi. Themes A to C detail the splintered social relationships and erosion of support that commence with the onset of caregiving responsibility. The final three themes (D-F) examine the long-term effects of this cumulative loss, eventually leading families into a zone of abandonment and isolation.

A. Erosion of social relationships

Family caregivers of people living with mental illness describe an experience of a gradual loss of social support networks. At the onset of the illness, these families are bolstered by a host social support networks including families (nuclear and extended), friends and community members. These networks are a wellspring of emotional and moral support. These support networks also provide physical support in terms of basic needs such as food and clothes to the affected patients and families.

When his illness started, all of us came together and made a decision to seek care...and community members were coming to visit us and gave us some food items...even when we were admitted at the hospital community members took an initiative to cook for him. They were very supportive and I appreciate that. - Female caregiver, age 59

Additionally, community leaders are also actively involved at the onset of the illness. They are informed about the patients' diagnosis of mental illness, and together with the families, the community leaders decide about the course of care. These community leaders lead other community members in supporting these affected families by mobilizing resources such as food to support these affected families.

At the start of the illness, when he began to destroy household items, I informed the village headman who advised me to visit health facility and he wrote a letter so that I could be assisted there [at the facility] ...he also asked the women in the village to help contribute food to help us. - Female caregiver, age 62

However, as the disease progresses, the people supporting the families start to withdraw their support because of the chronicity of the illness and the stresses that come with it. They stop visiting families frequently as before and other forms of support also begin to fade away. This leads to the slow disappearance of these social support networks, which gradually makes the families and primary caregivers isolated without physical, emotional and moral support.

After the onset of the illness people from the community and church were visiting me frequently but over time they stopped after seeing that the illness was chronic, I guess they were tired and I don't blame them for that... They were very supportive and I appreciate that. - Female caregiver, age 60

For some of these caregivers, even the relationships with their close family members become strained over time due to the stresses and hardships related to caregiving. For many of our participants, the strain on these relationships ultimately broke up long term relationships, with spouses seeking separation and divorce from the primary caregivers. Even their siblings, who were supposed to be a source of support to the primary caregivers also start to slowly distance themselves because of the troubling behaviors and the strain associated with caregiving, leaving primary caregivers to be more isolated without social support and connections. This has greatly affected them as they are left isolated and abandoned with care responsibilities as commented by this divorced caregiver:

My husband left me because of the illness of our son. He used to beat us and break things here at home, so he got angry and left me. He went to stay away from here, stating that I should seek help from my relatives. Since then, I have been struggling to take care of him.

- Female caregiver, age 54

B. Outright rejection from the community

Presence of mental illness in a family has resulted in families being stigmatized and rejected by the communities in which they live. For some of these interviewees, the shrinking of their social networks forces them to be alone shouldering the responsibility of caregiving which makes them unable to join friends and community members in community gatherings such as churches or weddings. Due to this lack of socialization, the community members react by isolating them from participating in community activities and sometimes ridicule and insult them.

The community members isolate me (caregiver). They say I do not join them in the community gatherings. With this, people conclude that I am arrogant and they don't even involve me in the community programs like 'food for work' (a community cash transfer program). - Female caregiver, age 60

Families are also excluded and discriminated against by their communities if they do not follow the communities' cultural beliefs on mental illness and the traditional course of care. For some of these caregivers, they experienced isolation and rejection from the communities they live in because of following other forms of care other than the one commonly used by the communities as explained by this caregiver.

The community members around here hate me, they advised me to take the client to a traditional herbalist who resides in this village but I refused and told them that I am a Christian and I do not put my trust in such people. So, because of that, they concluded that I am an arrogant person, and since then they isolate me in whatever they do. -

Female caregiver, age 60

Some of these families experience extreme measures of rejection where they are expelled from their communities because of disagreements with some community members and the behavioral problems of their loved ones. This forces them to wander around and relocate to other villages.

The community members led by the village head chased us away from our village because of the behavior of my patient. They just said your son is causing us trouble, take him with you and leave this community, so I wandered around and luckily, the head of this village accepted us and we built a small shack to be sleeping in there. - Female caregiver, age 67

C. Inadequacy of formal mental health care

Family caregivers describe the challenges they face when they try to engage in formal mental health care. With the loss of social support networks and struggling to contain the unpredictable nature of the illness, families desperately try to engage into the formal mental health care but the distance and the costs to get there makes it almost always impossible and hard for families as explained by this female caregiver.

Getting from here to the hospital, we start off in the morning before the sunrise and reach there when the sun is here [sunset]...and for an old woman like me it takes me the whole day to reach there. - Female caregiver, age 62

To get to the hospital from this village, we take many hours by foot...approximately six hours, but when we want to travel faster we hire kabaza (motorbike) which is very expensive. - Female caregiver, age 54

When these families try to overcome the long distance and costs to get to a health facility, they find that the nearest health facility is not ready to provide the services that the patient needs. The caregivers described that when reporting to health facilities, they frequently found that the facility does not offer medications for people living with mental illness. This made the continuity of care a challenge for our participants. Even when the medications were available at a given facility in principle, stock-outs were frequently resulting in disease relapses for patients.

For him to fall sick again and broke the glasses from the windows, the medications at the Hospital had run out and he did not take any treatment for a number of months which made his illness to come back. - Female caregiver, age 67

Apart from the lack of medications at the health facility, family caregivers also describe the dire lack of health workers trained to manage mental health conditions. They are often transferred to the district hospital where they are made to wait for specially trained personnel to give them care. If the person is not available, they are sent back to come again another time or are transferred to the mental hospital in the capital.

Last time I went to the health center, we waited for our doctor (mental health clinician) to come from the Boma (district hospital), but he did not come because of transport issue and we were sent back home without medications. And we were told to come again after two weeks. - Female caregiver, age 38

D. Despairing isolation

Faced with the slow disappearance of the social support networks, rejection from the community members and the challenge to access formal mental health care, family caregivers found themselves alone to deal with caregiving of the unpredictable illness. They have no one to share the caregiving responsibilities with, which forces them to constantly be present at home, glued to the patient in order to meet his or her needs and to surveil the patients' behavior.

I cannot go anywhere if there is nobody here to keep watch over him. I stopped visiting relatives and friends years ago. I can't even go to funerals or weddings in this community. I stopped going to church a long time ago. I am always on guard making sure that he is here and he is safe. My life stopped because of his illness. I can't do anything and am just isolated. - Female caregiver, age 62

My illness has affected my mother a lot because she has to fulfill all my needs as her son. She spends most of her time taking care of me instead of doing other things like businesses. - Male patient, age 33

The dire need for them to be constantly present to provide care to their loved ones prevents them from engaging in other activities of daily living. This includes essential activities such as working in their fields to grow crops for food.

I do not work as I used to do. I only spend a little time in the field doing farming...then I rush home in order to look for food so that I can prepare for him. So, let me say the first point is that I am unable to do reasonable farming. - Female caregiver, age 54

These demands of caregiving have even forced some of these caregivers to give up their income generating activities such as businesses and casual labors. This has made them impoverished as they fail to meet most of the basic needs for day to day life.

Previously, I was able to work in the field and sell some of the products to have some money for soap and other things but now we only rely on well-wishers to give us something to eat. That's the remarkable thing that has changed in our lives. - Female caregiver, age 60

E. Desperate Impoverishment

The presence of mental illness in a family and the demands of caregiving has left families impoverished. For these families, the presence of social support networks fills up the gap when there is a need for food and clothes. As these social networks begin to fade – and ultimately fail - families lose the ability to call upon others for help. Without help primary caregivers are left alone as sole caregivers, requires them to be present all the time to provide care. Providers

explained that the need to be present as sole providers have made them give up their income generating activities leaving them struggling to meet the basic needs.

Before his illness, I used to do a business of brewing and selling beer and also selling traditional baskets but I am no longer doing that business all my attention is on him. -

Female caregiver, age 60

Forced to give up their income generating activities, families try to find means to sustain their lives through local farming. However, they also find themselves unable to do reasonable farming due to the demands that come with being the sole provider. This pushes them further into poverty as they fail to afford food to last them all year round, making them sleep on an empty stomach.

Honestly, we struggle to find food almost on a daily basis...as you can see I am all alone here and I cannot go to the field to work during the cultivating season because of his illness. So, it has been a story since his illness, we sometimes eat and sometimes sleep without eating. - Female caregiver, age 62

As family caregivers lose their ability to sustain themselves, they are forced to take extreme measures of selling their belongings to generate some income that can allow them to afford the basic needs. But this makes them lose valuable possessions and assets that could have benefited them long term. This results in them going deep into poverty without anything to rely on.

I used to have goats around here, but all of them were sold helping to meet his demands. And in the former days, we could do many things together which now we are not able to do. - Female caregiver, age 60

I used to brew beer during the time when he was in a normal way though my friends passed on and that time had enough money and with the coming of his sickness, I lost all the money to the native doctors and nothing ever changed in his body. - Female caregiver, age 69

In the case where there is no hope, families take humbling measures of going around to the neighbors to beg for food. Providers explained that they go around the villages to beg for food and if they are lucky they are given some but if they are not lucky, they are not helped and it is not uncommon for them to go to sleep without food.

We usually beg from the surrounding neighborhood and other relatives and if successful then we find ourselves having food for both patient and the entire family, but if not, then we stay the whole night without taking any food, so sometimes we go to bed without eating anything even the patient himself. - Female caregiver, age 38

F. Extreme uncertainty about the future

The gradual disappearance of social support networks leaves family caregivers isolated and without moral, emotional and physical support. When they look around, they find that they have no one to share the responsibility of caregiving with which makes them the sole providers, shouldering all the responsibility of care. And this takes a great toll on their physical and emotional energy as this caregiver commented:

This is my thing [referring to the patient]. If I don't provide him with care who else can do it? It is my thing and I have to live with it. I don't have any other option but to just accept it. There is nobody I can handover this burden to. It's only me as his mother. - Female caregiver, age 62

With the caregiving demands of this unpredictable condition as a sole provider of care, family caregivers meet some challenges that they wish to share with others, but they find that there is nobody to talk to and that gives them mental fatigue to deal with as this mother lamented.

I am all alone with the patient, nobody comes to give me a hand not even any kind of assistance. I don't have anybody to share with the challenges and pain I am going through. - Female caregiver, age 60

Caregivers in our study were primarily mothers. They framed their caregiving responsibilities in these terms, reflecting that a kind of 'motherly responsibility' propelled them to provide care in such difficult circumstances. Aware that they had no help, these caregivers were gravely concerned about who would care for their children when they were no longer able to provide for them. This concern was particularly acute for elderly female caregivers, whose worries about the future of their children after their own passing caused them great concern, and sleepless nights:

I spend a lot of time thinking and crying. What will happen in the future for him [patient]? Is he going to get better? What if I die today, who will take care of him? -
Female caregiver, age 62

Yes, who else can support him apart from me? I am the one who brought him to this World that is why it is my responsibility to take care of him. You see, his siblings are away with their families I am the only one living here. His siblings have also their own responsibilities with their children. My only worry now is that I am getting old and I feel pain in my hands, I don't know what will happen in the future. - Female caregiver, age 60

DISCUSSION

The current study provides a rich description of the experience of family caregivers of people living with severe mental illness, highlighting the cultural dimension of the caregiving practices and their effects on patients and their caregivers. Our account of family caregivers of patients with severe mental illness in Malawi outlines the trajectory whereby caregivers are increasingly abandoned by families and communities, become trapped by their caregiving responsibility. At the onset of illness, these families enjoy the benefits of a complete and intact social support network that provides emotional, moral and physical support to the primary caregivers and to the families as a whole. But over time, these family caregivers go through a gradual painful journey of losing social support from the community members, friends, and family which pushes them into deep isolation. Left alone to provide care for the patient, caregivers make sacrifices by abandoning their income generating activities and selling their assets, which pushes them into a state of deep and desperate impoverishment. Stigma and rejection from the community also led to a state of social exclusion and abandonment, which induced grave concerns and worries for the future.

The study found that in addition to the disappearance of community and social support networks, caregivers also experienced a breakdown of the intimate family unit. Divorce and separation of the primary caregiver and the relocation of siblings away from the original family home left primary caregivers completely alone. This situation contrasts markedly with findings in other settings, notably in Nigeria⁶³ and China,⁵⁶ where family units remained largely intact and acted as a buffer against a broader erosion of support from communities. The important contrast between the Nigeria study and ours is that the people involved in the Nigeria study had regular contact with the health system while our patient population had no regular contact with the

health service. This suggests the importance of providing regular care for people living with mental illness, which could stem the breakdown of the vital supportive connections within the family.

This study found that all caregivers described an economic meltdown due to caregiving that left them in a state of desperate impoverishment. This confirms the findings of several studies that have highlighted the economic burden as a significant challenge faced by family caregivers in caregiving.⁶⁴ In a review of the economic burden of severe mental illness on family caregivers in Sub-Saharan Africa, Addo et al⁶⁵ attributed the productivity loss of a caregiver as the major cause of this economic burden. This productivity loss was extreme in our population because there was only one caregiver available without anybody to help share the responsibility of care. Our data highlight the economic implications of this isolation, as caregivers must forgo economic activities, which leaves them in poverty. In our population, all participants were farmers who grow crops for food and also sell some agricultural products to obtain money for other basic needs such as soap and clothes. And being a sole caregiver means not able to work in the field thereby having no food to eat and without produce to sell for income, which pushes families into desperate poverty. Many expressed the desperate need to be assisted with basic needs mostly food.

In this study, we found that families are stigmatized and discriminated against to the extreme level of hostility where they are expelled from the communities they live in, which pushes them into a state of what ‘social abandonment’ without social support and care. This is correlated with several studies which showed that families caring for a person living with mental illness are stigmatized and subject to discrimination.⁶⁶ The extreme hostility and expulsion of patients and caregiver from their communities has not been documented elsewhere in the extant

literature on mental illness in sub-Saharan Africa. We have uncovered this dire vulnerable – invisible population, and further study is warranted to better understand the extent of this problem.

Our study like other studies elsewhere, found that majority of the caregivers were women which reflects the cultural expectation of females carrying the caregiving role when somebody becomes sick in a family.^{67, 68} Within the context of rural Malawi, women are expected to manage the entire household which involves taking multiple tasks that also include farming, and this cultural expectation of carrying out the caregiving responsibility puts a great physical and emotional toll on these caregivers⁶⁹ leaving them into a vulnerable situation. This may be one of the many explanations that shows why women caregivers have high caregiving burden, burnout and emotional distress as compared to non-caregiver women.⁷⁰ As several studies have shown, female caregivers reported loss of social support networks as compared to men caregivers,⁷¹ this may be the reason why in our study found a highly significant social support splintered which adds to the vulnerabilities of these caregivers leaving them into isolation.

In our population, the majority of family caregivers were elderly women. This highlights an inversion of the standard social role occupied by female elders. This was an important observation because the standard social expectation in this context is that the young generation should be responsible to care for the elderly people, but in this case, it was the opposite. Caring for a person with mental illness as reported by several studies causes a significant physical, emotional, and financial burden to a family caregiver, and it becomes hard for the aging caregivers because they have to balance between the caregiving responsibilities and to manage the consequences of their own aging,⁷² putting them in a vulnerable state and at risk of depression, social isolation, and chronic disease.⁷³ In agreement with several studies, we also

found that elderly caregivers exhibited deep concerns and worry about the future of the patient when they are gone.⁷⁴ Caregivers may have these worries because they feel that there will be nobody to step in to take the responsibility of care for their relative when they are gone. This finding suggests that this problem exists at the intersection of mental illness and aging, suggesting that a more intersectional approach that leverages rights and resources related to mental health and aging may be appropriate in this setting.

The future worries of these caregivers are also compounded by the challenges they experience when they try to engage in formal mental health care. Their failure to consistently engage in care leaves them without hope that their loved one will one day live a meaningful life. There is a need for special community support programs that provide emotional support to these vulnerable populations to help them walk through the anxieties and uncertainty about the future, and they need also to be materially supported with basic needs such as food and soap, bearing in mind that they are unable to work because of what caregiving demands, and also their progressive weakness due to aging. Programs that provide emotional and material support to these caregivers will strengthen these front-line caregivers, with the dual effect of preserving their emotional and physical well-being and preserving the essential caregiving labor that they provide within the broader landscape of mental health care in Malawi.

We acknowledge that our study has several limitations. First, our sample was drawn from one region in Malawi which may limit transferability of our findings. As a qualitative study, our intent was not to produce generalizable findings; rather we wanted to develop an in-depth, detailed portrayal of the key components that mark the lived experience of family caregivers in this rural setting. Second, our sample was comprised of only people who had some contact with a health facility. Our study was, therefore, unable to capture the experience of caregivers who had

never sought care in the formal health care system. Looking at our findings, however, we feel that the experience is not much different as these people were also not constantly engaged in care and the solutions to address the specific needs of this population can apply favorably to both groups.

CONCLUSIONS

In settings where the delivery of care for individuals living with mental illness is provided primarily by families, it is important to understand the impact and complexities that caregiving has on family caregivers. This analysis did highlight the mechanism of embedded loss and the long-term effects of this cumulative loss has on a family caregiver and the patient. We have also demonstrated caring for a person with severe mental illness as a source of profound impoverishment. These findings have added to the available literature on the family experience when taking care of a relative living with severe mental illness. Results suggest the need to build community mental health services by decentralizing mental health services to all primary health care facilities that are near to the people. This can be achieved by providing training to primary health care providers on the management of people with mental illness and to continuously support them with a mentorship program to give quality care. Beyond the health facilities, services should also be provided in the communities with the involvement of community members themselves by identifying and training them as community health workers to be providing some basic mental health services and support to the affected families.

Our results also suggest the need to build community social networks of families to reduce isolation and the caregiving burden by allowing them to share their experiences and coping strategies to deal with the stresses related to care provision. The family support groups

could be an opportunity for collaboration with the formal mental health care system where a trained mental health worker can share educational messages with the affected families.

More research is needed to fully understand the experience of caregivers who are completely not engaged in care. There is also a need for implementation research to evaluate the impact of the proposed community support programs on the caregiving burden and social support networks.

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