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UNSUNG HEROES: THE PRIVATE AND PUBLIC TROUBLES OF FAMILY CAREGIVERS IN GHANA'S MENTAL HEALTH LANDSCAPE

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ABSTRACT

Background: The role of family caregivers (FCs) in the care for persons with mental illness is akin to numerous challenges. These challenges stem from dominant cultural beliefs which have shaped individual perceptions about mental illness.
Aims: The study explored the personal, social, economic and health challenges that family caregivers face while caring for relatives with mental illness at the Ankaful Psychiatric Hospital in Ghana. The symbolic interactionism perspective served as the theoretical lens for the study.
Methods: Guided by the qualitative research design, the study purposively selected and interviewed 15 family caregivers with mentally ill relatives at the facility.
Results: The study revealed that the roles of family caregivers casted a shadow on their personal, social and economic lives since they wallowed in chronic stigmatisation, social discrimination, social exclusion, negative labelling and financial constraints. FCs avoided social events to swear off public ridicule ensuing from their roles as caregivers.
Conclusion: Caring for persons with mental illness places an enormous burden on family caregivers in every facet of their lives. The combined impact on their personal wellbeing, financial stability, social relationship, coupled with lack of family support, highlights the urgent need for better support systems.

KEYWORDS: Private Trouble, Public Trouble, Family Caregivers, Mental Illness

INTRODUCTION

Family caregivers (FCs) play an important role in the care and healing process of relatives with mental illness (Albert & Simpson, 2015). Generally, their roles include the provision of emotional, physical and financial support to the mentally ill persons.

Based on their contributions to the care and healing processes, their roles became a globally accepted practice after the deinstitutionalization policy in the United States of America (USA) in the 1960s (Parker, 1993). The policy's principles referred to the need to develop psychiatric care that is closely linked to primary care and within the framework of the local health system.

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This ensured that mentally ill patients in the various mental health institutions were integrated into communities in aid for responsible family care. The policy improved the health status of the mentally ill thereby leading to the global acceptance of the practice. This led to a substantial shift from a hospital-based to a community-based system (Sharan & Krishnan, 2017). However, the global acceptance of family caregiving to the mentally ill was accompanied by some challenges for family caregivers.

In developing countries, these challenges stem from the dominant cultural beliefs which have shaped individual perceptions and beliefs about mental illness (Abdullah & Brown, 2011). Persons with mental illness and their families suffer from discrimination, social isolation and exclusion, stigma and other human rights violation issues (Avincan, et al., 2023; Yin, et al., 2020). In some instances, FCs fall short financially while caring for their mentally ill relatives (Anokye, 2018). Others also do not only feel guilty about their relatives' mental health condition, but get distressed from the lack of support from other relatives, friends and the society at large (Schulz & Sherwood, 2008). It is against this backdrop that the study explores the experiences of FCs of persons with mental illness at the Ankaful Psychiatric Hospital (APH). The study was guided by these research questions;

How do relatives' mental health condition affect the personal and social lives of FCs?

How do relatives' mental health condition affect the economic lives of FCs?

How do relatives' mental health condition affect the health of FCs?

Conceptual and Empirical Reviews

Mental illness is a disabling chronic condition that exposes victims to the risk of other health problems (Prince et al., 2007). It is a health condition that affects the mood, thinking, and behaviour of its victims (Johnstone, 2001). Before the 17th century, persons with mental illnesses were seen and pronounced as "mad" (Zechmeister, 2005). In the 18th century, a strategy was developed to remove all "mad" people from the streets to mental asylums where they were kept in chains and straitjackets to restrain and treat them. However, the growth of public mental health education in the 19th century influenced people to understand mental illness as a treatable ill-health condition (Van Eeuwijk, 2006). As a result, "mad" people were freed from their physical restraints for medical treatment. More importantly, the deinstitutionalization policy in the U.S.A. ensured that admitted mentally ill patients in mental health institutions were discharged and integrated into the society to aid family care and swift healing (Parker, 1993).

This policy posed challenges to families because of the perceptions associated with mental illness. The challenges varied due to the differences in victims' background characteristics (Eapen & Ghubash, 2004; Pinquart & Sorensen, 2006). Females usually experience less challenges as compared with their male counterparts because of socialisation. Predominantly, women are socialized to nurture, provide help, and care for others (Pinquart & Sorensen, 2006). Regardless of the gender, occupation, and educational level, family caregivers experience challenges while providing care for relatives with mental illness.

Caregiving and the caregiver: The experiences of family caregivers

Mental health condition interferes with one's independence (Jimenez et al., 2013). In such a situation, the presence of a caregiver is crucial. Caregiving refers to the support provided to individuals who are unable to function independently (Costa-Font et al., 2017). Generally, it involves activities such as assisting with personal hygiene, medication, visiting treatment centres, emotional and financial support (Sreeja et al., 2009; Von Kardorff et al., 2016). Such care is provided either voluntarily or for a fee. However, FCs are usually not paid for their services because of their relationship with the patients.

Caring for relatives with mental illness has physical and emotional implications on caregivers (Breitborde et al., 2010). In Ghana, family caregivers receive little or no support from the families and the State, which exposes them to numerous challenges during caregiving (Anokye, 2018). Also, family caregivers suffer public ridicule during social engagements like weddings, funerals and meetings. Tawiah et al. (2015) further stressed that this stigma is sometimes extended to the entire family of the caregivers.

In a study by Ae-Ngibise et al. (2015), on the experiences of caregivers of people living with mental illness from Ghana, it was reported that FCs experienced huge burdens including financial losses, lack of or minimal support networks, social exclusion, health challenges, and constraints from centralized mental health services. They found that treating mental illness was expensive, which posed stress on caregivers.

As a result of the perception that there is a connection between mental illness and spirituality, FCs are often alienated from the wider society (Robinson-Whelen et al., 2001). The perceived reason is that a FC living closer to a mentally ill relative is either possessed or has a strong soul that cannot be defeated by the "spirit of madness". Because of their perceived spiritual fortitude, FCs are usually labelled as evil in the society (Tawiah et al., 2015).

Theoretical Underpinning

The symbolic interactionism theory, developed by Blumer (1969), underpinned the study. The theory is premised on three main ideas; humans act toward 'things' on the basis of the meanings that the 'things' have for them; the meanings of 'things' are derived from social interaction among people; and these meanings are dependent on and modified by an interpretive process of people through interactions. The focus here is on the meaning, which is defined in terms of action and its consequences. For example, the meaning of a "yawn" could be interpreted in many ways to include: feeling sleepy, hunger, tiredness or boredom. The meaning of a 'thing' resides in the action that it demonstrates.

Relating the assumptions to mental illness, the theory demonstrates that the meaning individuals attach to mental illness influences their reactions towards it. When they perceive mental illness as an evil disease, their actions towards persons with mental illness, their relatives and caregivers, through interactions, will include unfriendly gestures and postures, silence mood, spitting, cheeky responses and name calling. Family caregivers, in response to the pressure from the society, will distant themselves, which can affect the caregiving roles.

METHODS

Design

The study employed the qualitative research design. Since the study explored the experiences of FCs with their caregiving role, the design was appropriate to retrieve in-depth insights from the participants. All FCs who had their mentally ill relatives on detention and admission during the study period at the APH constituted the study population. The study was approved by University of Cape Coast Institutional Review Board (with ID: UCCIRB/CHLS/2020/06) and the Ankaful Psychiatric Hospital Research Ethics Review Committee. In addition to reviewing the instrument, the Board assessed whether the study adhered to the core values of academic integrity namely; honesty, trust, fairness, respect, responsibility and courage.

Recruitment

The FCs were purposively selected based on the following criteria: Their mentally ill relative had been on admission either at the ward (for those with severe cases) or at the psycho/detention unit (for those under review) during the study period, had suffered the condition for at least six months from the time of the study and the FC was the main caregiver of the patient.

One hundred and ninety-seven (197) FCs visited the APH during the study period and they were checked against the inclusion criteria. Out of this, 15 of them with different backgrounds in terms of sex, age, religious affiliations, marital status, level of education, and occupation qualified and were recruited as study participants. The diverse nature of the participants helped to explore different experiential situations for the study. It should be noted that although the number seems small, it allowed us to learn and retrieve in-depth data from the participants. Also, considering the issue of saturation as espoused by Guest et al. (2006), having 15 participants for this study was suitable as no new information was discovered after the 15th interview.

Interview and consent process

An in-depth interview (IDI) guide was used for the data collection. The IDI guide helped us to explore and gather experiential narratives from the FCs. Also, the instrument allowed for further probes to some of the responses. This data collection exercise took a period of three weeks and the data were collected through one-on-one interviews. This allowed the participants to freely share their experiences. Nonetheless, they were taken through some form of counselling by the mental health workers to manage any (potential) emotional feelings. Each interview lasted between 30 and 40 minutes.

To protect the privacy and emotional health of family caregivers, the research team sought consents from them and they were allowed to skip sensitive questions or withdraw from the study whenever they felt uncomfortable.

Analysis

The data collected from the field were transcribed and translated verbatim from the local languages into English for the analysis. The analysis was done per the six phases of Braun and Clarke's (2006) thematic analysis plan: familiarization with the data set, generation of codes, searching for themes, reviewing themes, defining and naming themes, and report writing. Through that, the data were organized into three main themes reflecting the research questions. The data were presented in the form of descriptions and narrations with the use of quotations from the participants' voices. These were then discussed in relation to the related literature.

Patient and public involvement

Issues on mental illness are sensitive and could trigger emotional discomfort. Therefore, the Ankaful Psychiatric Hospital Ethical Review Committee reviewed the content of the interview guide to ensure that the participants were protected from harm. The committee assisted with introducing the research team to the various heads and family caregivers who visited the relatives at the facility. The rationale was for the participants to familiarise with the research team so that they freely express themselves. The data analysed and write up were discussed with the FCs (debriefed) to ensure validity and reliability.

RESULTS

This section presents the background characteristics of FCs as well as the key findings of the study. The main findings are organized in three broad themes: personal and social experiences, economic experiences, and health experiences of caregivers as they dispatched their caregiving roles on relatives with mental illness.

Background Characteristics of Family Caregivers

The background characteristics of FCs covered their sex, age, religious affiliation, marital status, level of education and occupation. The study showed that more than two-thirds (11) of the FCs were females, probably because the social structure of Ghana has assigned caregiving roles to women. The ages of the FCs were categorised into three cohorts (29-38years, 39-48years, and 49+years) with the youngest being 29years and the oldest being 61 years. Most of the FCs were above 40years. Also, a significant number of FCs were married Christians with formal education. Caregiving often necessitates significant financial resources. Therefore, FCs need a sustainable economic activity to enable them support their relatives with mental illness financially. The data showed that all the FCs, apart from a student, engaged in income generating economic activities within the formal and informal sectors of the economy.

Experiences of Family Caregivers

Over the years, family caregivers of persons with mental illness have experienced several challenges. In this study, FCs identified personal, social, economic and health problems with their caregiving roles to mentally ill relatives. The sections that follow take this up for discussion.

Personal and social life of family caregivers

All the FCs asserted that their relatives' conditions have taken a toll on their personal and social lives. FCs gave series of accounts to buttress their experiences. A 49-year-old female FC indicated that:

…it has not been easy at all. I can't do anything…I can't go anywhere…I am just shy; people just stare at you when you step out…the stigma alone...hmmm…I always cry at night…they think we used my daughter for car rituals. That means we used our daughter for a car…just a car…could you believe that? she sighed. In relation to their personal and social lives, FCs recounted days that friends and community members publicly stigmatized, discriminated and emotionally abused them.

As a result, most of the FCs were shy and afraid to step out because of the relatives' health condition. FCs avoided social events such as weddings, funerals and religious ceremonies to prevent public ridicule from the community members, who often stare and mock them. These public reactions sometimes lead to trauma. Others also lamented that they lost contact with their close friends, who mysteriously stopped visiting because of the community's perception on mental illness.

Economic life of family caregivers

On how the role of caregiving affected the economic lives of FCs, participants stressed that their relatives' mental health conditions have affected their paid-work output and financial stability. Some of them alluded as follows:

We (the family) have lost everything, my work…my house…everything. It's expensive to treat these conditions. And I have borrowed money all around to the extent that I have exhausted all my borrowing options…not even a loan from the bank. The medical bills are no joke, if you don't have money, pray that none of your relatives get this kind of condition" (a 49-year-old male FC).

FCs mentioned that their caregiving role caused financial stress. This is because, they spent more time with mentally ill relatives at the expense of their income generating activities. When they were financially handicapped, FCs sought for aid from their significant and generalised others. In the process of caregiving, some FCs also lost their paid jobs, making it extremely impossible to finance the health needs of affected relatives. FCs heavily expressed their disappointments in relatives who failed to provide financial aid in the care and treatment processes.

Health of family caregivers

In addition to FCs' personal, social and economic difficulties, the study examined how their caregiving roles affected their health. The following responses were gathered;

…she's the one that's sick so why should that affect me, especially my health…yes, it's true that I am pumping huge money into the treatment and now business is not that booming, and no one wants to get closer to us again, but I am not troubled at all. I know I will bounce back soon (she smiled disappointedly) (a 37-year-old female FC).

…because of the stress and stigma, our parents look like they are 150 years now (he smiled sadly). I know they are very hurt and sad from within, but what can they do? (a 29-year-old female FC).

This is a strange situation to the family. The treatment is expensive, and the stigma…our father even died out of it. (a 29-year-old female FC).

It was evident that caregiving did not significantly deteriorate the health of caregivers. That is, their relatives' mental health condition had no major effect on FC's personal health. In fact, the FCs only emphasised overthinking, stress and stigma as minor health issues emerging from their caregiving roles, which they can handle. Conversely, a FC attributed the cause of her father's death to her (the FCs) relative's mental health condition.

DISCUSSION

The analytical review of the data portrayed a decline in the personal and social lives of family caregivers who vowed to support relatives with mental illness. This finding confirms Tawiah et al. (2015) and Mfoafo-M'Carthy and Grischow (2022) study which reported that FCs and the family of persons with mental disorders experience social stigma. Caregivers suffered from all forms of prejudice and discriminations from the community members because of the social tags and labelling associated with mental illness. This finding was in line with Ae-Ngibise et al. (2015) and Robinson-Whelen's et al. (2001) assertions that FCs of persons with mental illness were socially excluded and ridiculed publicly; thereby reducing their social interactions and contacts. The presence of their mentally ill relatives in the lives of caregivers marred joking relationships that existed between them and their social groups; causing social disjunction such as conflict, separation, trauma, abuse and stigma.

Tawiah et al. (2015) similarly reported that FCs of persons with mental illness were stigmatized and mocked, as others were labelled with names.

From the symbolic interactionism standpoint, the FCs read meanings into the actions of the people in their communities towards them. These actions included stigma, abuse, public ridicule, mocking, name calling, and neglect. It should be noted that, the actions posed negative consequence on them, hence, affected the interactions between them (the FCs and the people). Invariably, they (FCs) had no choice than to cease going out to public places as they realised that, limiting or cutting social interactions with the people is beneficial as far as their caregiving roles are concerned.

The findings of the study depicted that caregivers were financially handicapped because they spent a lot of money on managing the health conditions on their relatives. These findings concurred with Anokye's (2018) argument that FCs faced financial problems when seeking for treatment for their relatives' condition. FCs indicated that they had no problems with health resulting from caregiving roles. This finding diverges Schulz and Sherwood's (2008) assertion that some FCs were psychologically affected by the mental health conditions of their relatives.

CONCLUSION

The study at the APH established that caring for persons with mental illness came with some negative experiences. These experiences were seen in their personal, social lives and economic lives. Family caregivers experienced stigmatisation, social exclusion, name calling, and financial challenges. Since social stigma associated with mental illness affected an entire family of the mentally ill, some family members felt reluctant to support the care and treatment processes of relatives with these conditions. To help FCs of persons with mental illness, there is the need for the APH management to create informal groups of FCs to share their challenges with experienced counsellors during their visits at the facility. This will relieve them from emotional and psychological challenges. Also, stakeholder institutions like the Ministry of Health, Mental Health Authority, Ghana Health Service and other related NGOs should intensify education to the general populace on mental health through engagements with the media, schools, religious organizations, and community information platforms.

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