

Unfamiliarity and Perplexity of caregiver families' experiences in living with chronically ill family members in Addis Ababa, Ethiopia: A Qualitative Study

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Abstract

Background: The most pressing health and social issue confronting contemporary families have been chronic illness. Families are usually the ones who take the caregiver roles for their chronically ill members. Thereby, they usually endure and encounter perplexity owing to unfamiliarity with the illness, its symptoms, and treatments. This study aimed at revealing the perplexity that caregiver families usually experience owing to their unfamiliarity with chronic illness when living with and caring for chronically ill family members.

Methods: The study was conducted from September 2019 to January 2020. It used a phenomenological study approach to collect and analyze qualitative data collected through twenty semi-structured interviews over a period of five months. Participants were recruited from Black Lion Specialized Referral Hospital (TASH), Addis Ababa, Ethiopia.

Results: The study identified a lack of knowledge about or unfamiliarity with chronic illness, its symptoms, and treatments as the challenge that caregiver families of the chronically ill often face. A lack of knowledge has affected the caregiver families in three main ways: 1) increased risk of developing chaotic emotions and behavior; 2) difficulty to understand and provide the best care that the chronically ill requires; and 3) causes of strains in family interactions, usually between chronically ill and caregiver families. According to the study's findings, unfamiliarity with chronic illness and its treatments had a significant impact on overall family stability, everyday social relations, and functioning.

Conclusions: Families often assume caregiver roles for chronically ill members. Even though unfamiliarity with chronic illness and its treatments have a debilitating effect on overall family stability and functioning, Ethiopian public health policy has paid less attention to it. This study gives emphasis on the importance of raising public awareness about the growing impact of chronic illness. Therefore, it recommends that, first, attention be paid to including the growing problem of chronic illness in the public policy agenda; and, second, efforts be made to improve public knowledge about the growing impacts of chronic illness, enabling both the chronically ill and the caregiver to mitigate illness-born perplexities.

Keywords: Caregiving families, chronically ill, chronic illness, perplexity, unfamiliarity

Introduction

The most pressing health and social issue confronting contemporary families has been chronic illness, such as cancer, diabetes, hypertension, and so on (WHO 2019). The global prevalence of chronic disease and related illnesses is rapidly increasing. Chronic diseases accounted for approximately 60% of the 56.5 million total reported deaths worldwide in 2001, accounting for nearly 46% of the global disease burden (WHO 2002). By 2020, the burden is expected to increase to 57 %. It has posed a serious threat to the global population's health (Bauer et al. 2014; Nugent 2008; WHO 2011). The World Health Organization noted in its 2010 report that chronic diseases, such as diabetes, cancer, cardiovascular, asthma, and arthritis, accounted for nearly two-thirds of deaths worldwide (WHO 2011). The magnitude of deaths from chronic disease is anticipated to increase from 38 million in 2012 to 52 million by 2030 (WHO 2014). Similarly, as WHO stated in its 2011 report, chronic illnesses are the leading causes of death, accounting for 60% of all deaths worldwide.

Despite widespread lack of knowledge and attention, chronic illness has had a significant impact in low and middle-income countries (LMICs). It accounts for 80 percent of mortality in low- and middle-income countries, making it one of the most serious threats to people's health in these countries (WHO 2011; Wonde and Boru 2019). In Ethiopia, there is consensus among experts that chronic diseases are becoming rampant health and social problem (Dejene et al. 2014; EPHA 2012; Wonde and Boru 2019). According to Prevett (2012), the overall prevalence of chronic disease in Ethiopia is 8.9 %. However, it has received insufficient consideration in the country's public health policy. Moreover, in Ethiopia, there are scant studies on chronic disease in general and family experiences in particular (EPHA 2012; Kiflie, Jira and Nigussie 2011; Wonde and Boru 2019). Chronic disease is usually regarded as a family disease because the diagnosis of a family member with chronic disease poses a direct threat to everyone's lives, especially the patient's family. Nonetheless, studies in the field of chronic disease

have primarily focused on the experiences, perspectives, and challenges of patients. Less attention has been paid to the families' perspectives, experiences, and challenges in living with and caring for chronically ill family members (Bailly et al. 2015; McNamee and Mendolia 2014).

Chronic illness such as cancer, diabetes, stroke, asthma, cardiovascular disease, etc., is a long-term and incurable condition without definitive treatment, requiring lifelong support and care (Dobbie and Mellor 2008). Living with a chronic illness affects a person's physical, emotional, and social well-being (Clark 2012). Similarly, living with a chronic illness endangers the lives of everyone, especially the patient's family. Chronic illness is a permanent condition that becomes life itself; as a result, the family cannot escape the effects either. When a family member has a major chronic crisis, it leaves an overwhelming imprint on the rest of the family members, similar to family system theory assumptions (Newbould et al. 2006; Newcom 2004; Pierret 2003). The family develops unstable experiences not only because of the sick individual but also because of the illness's effects on their lives. In the families of chronic patients, the presence of the disease creates a sense of powerlessness, with an overall feeling of behavioral and mental anguish, constraint, and limited or no support, resulting in alienation (Öhman and Söderberg 2004).

Moreover, the diagnosis of a family member with a chronic disease usually forces the entire family members to assume caregiving roles and provide the best care that the patient requires. However, caregivers' experiences are significantly influenced by their prior or post-knowledge of the illness, its symptoms, and treatment. Families' reactions to a stressful chronic health crisis are heavily influenced by their prior or post-knowledge or familiarity with the illness (Kebede and Kebede 2016; Deist 2013; Thompson 2009). However, studies have revealed a knowledge gap regarding chronic disease in general and family experiences of living with chronically ill family members in particular (Abdella and Mohammed 2013; Abera 2000; Berhane et al. 1999). According to the Ethiopian Public Health Association (EPHA) report, the low level of public awareness about chronic illness is partly the result of poor attention given to the problem and the provision of essential information at the country level (EPHA 2012; Prevett 2012; Wonde and Boru 2019).

This study based the family system theory. The theory asserts that caregiver families usually face challenges when living with chronically ill family

members. According to the theory, when a family member suffers from a major chronic illness, it significantly influences the experiences of the rest of the family members (Newbould et al. 2006; Newcom 2004; Pierret 2003). As a result, studying and understanding the perplexities that chronic illness can cause on chronic patients and families of chronically ill family members owing to unfamiliarity with chronic illnesses and their overall complications can therefore be important for all concerned bodies (government or non-governmental organizations, NGOs) working in the public health sector. First, to enhance their knowledge about and give sufficient attention to the problem of chronic illness in public health policy; and secondly, to enhance public awareness regarding chronic health crisis and its debilitating effects thereby enhancing their capability in managing the effects of the illness. Therefore, the purpose of this study was to uncover the perplexities that caregiver families usually face when living with chronically ill family members, owing to their unfamiliarity with chronic illness and its complications.

Materials and Methods

Study Approach: The study was conducted from September 2019 to January 2020. This study employed a phenomenological study approach with a qualitative research method. It used a phenomenological study approach to collect and analyze qualitative data. According to van Manen (2016), the phenomenological research approach provides in-depth and interpreted data as well as an understanding of everyday social phenomena (experience, perspective, and histories). Therefore, the study used phenomenology to investigate the essence of families' experience in living with chronically ill family members. It used specifically to understand the perplexities that caregiving families usually face owing to their unfamiliarity with chronic illness when living with members with chronic illnesses.

Participants and Sampling Procedures: The study recruited participants, caregiver families living with cancer, diabetes, and hypertension patients. It was participated a purposive sample of 10 families living with chronically ill family members. It included two family members from each successfully contacted family to maintain an in-depth understanding of the phenomena studied. Thus, the numbers of participants were 20 in total (13 women and 7 men), between the ages of 19 and 31. Of all the participants, 12 were students, and eight were in paid employment during the study period.

The study recruited the participants from Black Lion Specialized Referral Hospital (BLSRH), Addis Ababa, Ethiopia. BLSRH was selected because it was the only public hospital in the country during the study period to treat chronic illnesses, including cancer, diabetes, and hypertension. The following were the inclusion criteria for participation: (1) must be families of the chronically ill; (2) must be families with the chronically ill members whose diagnosis was made at least three or more months prior; and (3) the participants must be family members who were still living in the home with the chronically ill. The study contacted a nurse at the healthcare center who was chosen at random to initiate contact with families of chronic patients who met the eligibility criteria and expressed an interest in participating. Each participant was contacted via telephone to arrange and conduct the interviews.

Data collection: The study collected qualitative data through twenty semi-structured interviews, for a period of five months (from September 2019 to January 2020). The interviews were designed to allow participants to share their experiences while also understanding more about the issue under investigation. The interviews were conducted to gain a better understanding of caregiver families' perplexity about living with chronically ill family members owing to unfamiliarity with the chronic illness, its symptoms, and treatment options. During the interview, participants were encouraged to narrate their experiences because according to Kvale and Brinkmann (2014), a qualitative research interview is a specific form of conversation that aims at understanding the dimensions of the interviewees' life world. The interview-guiding questions were prepared ahead of the fieldwork. Each interview lasted 40 to 60 minutes. It was held in mutually agreeable locations to ensure the convenience and comfort of the interview participants. The number of participants was determined by the amount of data collected from each study participant. Thus, after conducting 20 interviews, the researcher concluded that the data was saturated with descriptions of chronic illness experiences. The researcher carried out all the interviews.

Data Analysis: Data analysis occurred concurrently with the data collection activities. The interviews were digitally recorded and transcribed from tapes in Amharic, the local language. They were then translated into English. The collected data was manually processed. The goal of qualitative data analysis was to create a detailed, systematic record of the themes and categories discovered during the interviews. Finally, the study used the thematic analysis method, as described by Kiger and Varpio

(2020), which entails identifying patterns or themes within qualitative data.

Ethical Issues: The study received ethical approval from Addis Ababa University, Department of Sociology, prior to fieldwork. Verbal consent was obtained from participants prior to the interview. The study assured all participants that their participation was entirely voluntary and that they could opt out at any time. It took great care during the interview to protect each participant's anonymity and to store records on a secure personal computer. It also assured participants that the study's findings would be presented in a confidential and anonymous manner.

Finding

Participants' profile: This study included caregiver families who were living with and caring for family members who had cancer, diabetes, or hypertension diagnoses. Participants were families with chronically ill members whose diagnosis was made at least three or more months prior. They were contacted in a healthcare setting while they were with chronically ill family members who were undergoing treatment. The study included 20 participants in total, 13 females and 7 males between the ages of 19 and 31. During the study periods, all of the participants were unmarried and lived with their families. Twelve of the participants were students, and eight were working during the study period.

Knowledge-gap and consequential troubles: Since the onset of chronic illness, families have been the primary caregivers for a family member diagnosed with chronic disease. However, prior or post-knowledge about the illness and its treatments has a significant influence on their responses to providing the best care. According to the study's findings, a lack of knowledge about or unfamiliarity with the chronic health experience was a crisis that caregiving families usually face in order to understand the patient's illness experiences and provide the best care. A lack of knowledge about the disease and its complications was acute and had significant effects on caregivers' ability to provide the best care to chronically ill family members.

When the doctor notified us about our mother's diagnosis, we were unfamiliar with the illness and knew nothing about the treatments used to manage the situation. We did not think treatments were even possible. As a result, we often experience perplexity to understand her situation and provide the best care. We even thought she would die right away (Participant 1, Male, 25).

Unfamiliarity with or a lack of knowledge about diseases, symptoms, and treatments, regardless of

literacy level, was one of the common challenges that caregiver families usually faced in living with and caring for chronically ill family members. Due to a lack of knowledge about the illness, families assuming the caregiver role often experience perplexities.

Our dad is diabetic. When we heard from the doctor about his diagnosis, it confused us because we knew nothing to do and provide the help dad needs. Furthermore, we did not know whom to consult about the everyday situations because we never even managed to get support from health workers (Participant 12, Male, 27).

Chronic illness, according to the findings, has chaotic effects on caregiver families of chronically ill family members. This current study identified three major challenges that caregiver families usually face owing to their unfamiliarity with the chronic illness, its symptoms, and treatments.

Risk of developing chaotic emotion and behavior: A lack of knowledge about chronic illness usually has a chaotic impact on families who are caring for family members with chronic illnesses. It risks families to develop and experience chaotic emotions and behaviors such as anxiety, confusion, hopelessness, depression, and fear in the family. It was indeed partly owing to families' lack of knowledge about the illness and treatments to provide the best support to the person under their care. They sometimes would not think treatments were possible. As a result, the onset of the disease often ends the rest of the family to experience and develop emotional and behavioral turmoil due to their fear of losing the chronically ill family member and their inability to provide the best care.

Because of lack of knowledge, we did not even see any hope and thought our mom would not survive. We never even thought treatments were possible. As a result, we often fall into anxiety, fear, and hopelessness thinking about the future hassles related to her death. We thought that we were on the verge of losing our mom (Participant 3, Male, 28).

Following a family member's diagnosis with chronic illness, unfamiliarity with the disease diagnosed and the inability to know and provide the best care is a challenge that usually results in chaotic emotion and behavior in the overall family experience.

When we confirmed mom's diagnosis with cancer, crying, anxiety, confusion, and unstable feelings were some of our experiences because of unfamiliarity with the illness and its treatments (Participant 10, Male, 27).

Inability to understand and provide the kind of care needed: Unfamiliarity with the illness, its symptoms, and its treatment has an impact on the caregiver families' ability to understand and provide the best care. The onset of chronic disease in a family member increases the burden on the rest of the family members in terms of caregiving because chronically ill family members often spend the most time at home under their families' care. However, families' response to provide the best care has been determined by their knowledge of the disease and treatments.

Our dad is diabetic. At first, none of us knew about disease and its treatment. We never also received counseling services from the health workers to empower us to understand and provide the best support we could. Therefore, we usually experience anxiety and confusion about what to do. We had no idea how we could help him (Participant 16, Male, 28).

Our father is diabetic, and when we heard his diagnosis, we were confused because we were perplexed because we had no idea how to help him. Furthermore, we had no idea whom to consult about the everyday situations we faced because we never even managed to get support from health workers (Participant 15, Female, 24).

Diabetic and hypertensive patients are used to follow unhealthy eating practices. The findings revealed that a lack of knowledge about the disease's behavior often leads to frustration among caregivers. Patients with diabetes and hypertension, for example, have specific dietary practices to manage their health conditions. Thus, as primary caregivers, families are expected to know the kind of care required, such as in food preparation. Nevertheless, a lack of knowledge about the disease's behavior usually causes anxiety and frustration within the family. The study revealed the difficulty in understanding the person's agonizing experiences in order to provide the best care possible owing to their lack of knowledge or unfamiliarity with the illness's behavior and the care required to control the pain.

We had no information or knowledge about the disease when the doctor confirmed mom's diagnosis with cancer, and we were unaware of the treatments used to manage the situation. We did not believe that treatments were possible. As a result, we frequently face difficulties in understanding her situation and providing the best support or care that our mother requires. We even thought she would die right away (Participant 1, Male, 25).

We have many hard times, especially when mom is in pain. Whenever our mom is in a pain, we often get

into confusion and anxious experiences because we usually face problems getting a sense of her pain and providing the care used to manage her situation. You do not know how it feels and hurts when you see her on the bed suffering and when you are unable to do anything (Participant 4, Male, 28).

The study findings revealed that, in addition to causing chaotic emotions and behavior, unfamiliarity or a lack of knowledge about chronic illness and its treatments has a negative impact on caregivers' ability to provide the best support for a patient under their care. Furthermore, a lack of knowledge about chronic illnesses causes strain within the family, resulting in unhealthy family interactions.

Strains in the family interactions: When a family member develops a chronic illness, the presence of the illness is enough to cause stress. Unfamiliarity with the chronic disease can make things more chaotic in managing the situations. It sometimes causes unhealthy relations inside the family, usually between the patient and the rest of the caregiver family. Chronic illness causes the patient to pass through various painful challenges and changes in their physical, emotional, and behavior.

Mom's legs swelled because of the chemotherapy, making her feel unattractive and socially isolated. Her dress has changed considerably. As a result, she often experiences anxiety, loneliness, melancholy, and a sense of impending doom. She continued to complain about almost everything, including life, God, fate, drugs, and nearly everything else (Participant 2, Male, 27).

We often spend hard times, especially when mom is in pain. The pain often makes her hot-tempered and verbally inconsiderate. We do not know how we could help her. As a result, we stay away until she gets calm (Participant 2, Male, 27).

The study's excerpts shown that caregiving families usually face hard times, especially when the patient experiences pain. Patients with chronic illness at times of pain express their feelings and resentments toward their family members.

The study revealed that families' inability to understand patients' pain and the chaotic changes in emotions and behavior frequently cause disagreements and conflicts between the chronic patient and the rest of the family. However, as the finding indicated, it was not because of caregiving families' negligence. As a caregiver, families often provide the best support.

We always do what we can to get him (dad) out of the anxiety brought by the illness, despite his unceasing

complaints and desperate feelings. It is confusing and challenging to understand him. Therefore, sometimes we end up in disagreements and conflicts (Participant 5, Female, 27).

Dad is not interested in hearing from any of us. He becomes enraged and refuses to take his meds. It stings when he keeps saying, "I want to die." We are not sure how we can help him. As a result, disagreements and conflicts are common (Participant 7, Female, 29).

According to the findings of this study, a lack of understanding due to unfamiliarity with the illness and its overall complications usually cause more resentment within the family, resulting in an uneasy social environment.

Discussion

This study aimed at revealing the perplexities that caregiving families usually experience in living with chronically ill family members owing to their unfamiliarity with chronic illness and its overall complications. The findings of the study revealed that the onset of the chronic illness to a family member usually causes families to step up into caregiver roles because the chronically ill often receive their treatments at home under their family members' care. In other words, the families of the chronically ill take on the roles normally played by healthcare centers under the supervision of healthcare experts. Hence, understanding the illnesses, its symptoms, and treatments becomes very crucial for families who take on and perform caregiver roles. The families' ability to manage and respond to a crisis like a health crisis depends on knowledge about the problem and its treatments (Walsh 2003). Studies (Deist 2013; Walsh 2003) indicated that understanding the crises makes caregiver families better able to maintain a sense of control over illness-causing situations, which fosters confidence that their circumstances will ultimately work out positively. Understanding the illness was significant to cognize the patient's experiences, making it easier to adapt and adjust to illness-born situations (Walsh 2003).

When a family faces an unexpected health crisis, like chronic illness, they usually attempt to respond to the illness's inherent challenges. Caregivers' knowledge or familiarity with chronic illness, its complications, and treatments are indispensable and determinant of how they respond to the challenges of the chronic health crisis. Similarly, studies have supported the importance of knowledge about phenomena such as chronic illness (Deist 2013; Prevett 2012), because understanding some of the characteristics of the illness may make it easier to provide the best care for the patient. In contrast to this fact, this study revealed

that one of the most significant issues that caregiver families of the chronically ill faced in Ethiopia, regardless of literacy status, was a lack of knowledge or information about the disease diagnosed its symptoms, and its treatments. According to the study findings, a lack of knowledge and information posed a serious challenge. The caregiver families usually have difficulty in understanding the chronic illness, its symptoms, and the struggles of the chronically ill. Similarly, previous studies revealed that a lack of public knowledge about chronic illness as the health and social challenges in Ethiopia (Abdella and Mohammed 2013; Abera 2000; EPHA 2012; Wonde and Boru 2019), which has affected caregiver families of the chronically ill in a variety of ways. The study's findings revealed that a lack of knowledge concerning chronic health crises and their overall complications causes the caregiver families of the chronically ill to develop chaotic emotions and behavior, such as anxiety, confusion, depression, fear, etc. It was partly because of the unfamiliarity with disease and its treatments. According to Prevett (2012), when someone develops a chronic health crisis, families usually attempt to provide the best care that the patient requires. However, due to a lack of knowledge or unfamiliarity with the disease, the families with the caregiving role usually face challenges in understanding and providing the best care for the patient. Moreover, caregiving families often develop fear because of a lack of knowledge about possible medication or treatments. Thus, the family often experiences confusion and unstable emotions and behavior.

Lack of knowledge about the illness and its treatments also affects the family's ability to provide the best care that the person needs. Understanding the phenomenon, such as chronic disease, its symptoms, and treatments was found to be important because understanding some of the characteristics of the illness may make it easier to provide the best care for the chronic patient (Deist 2013; Prevett 2012). Patients with chronic diseases, such as diabetes and hypertension, usually have unhealthy eating habits. As caregivers, families of the chronically ill are expected to know and provide care in the ways that the patient requires, in food preparation. However, the findings of the study showed that families' ability to provide the best care is hampered by unfamiliarity with chronic illness and its treatments. It was also the cause for frustrations caregiver families' experiences, which hampered the family overall stability by creating unhealthy family relationships, usually between the chronically ill and the rest of the family.

The findings also revealed that lack of knowledge has more effects, such as causing unhealthy relationships

within the family, usually between the patient and the rest of the family members, which results in chaotic emotional experiences for both the patient and the rest of the family members. Caregiver families of the chronically ill usually find themselves in conflicts owing to a lack of knowledge about the illness's behavior, symptoms, and treatments, resulting in a lack of understanding between the chronically ill and the rest of the family. Similarly, previous studies indicated that living with the chronically ill usually hampers and strain family relations (Mengistu 2013; Biru et al. 2015). As primary caregivers, families must deal with the chaotic effects of the illness. The finding, however, revealed that the onset of the disease and associated changes in emotions and behavior could often lead to unhealthy familial relationships. Patients with chronic illness usually express resentment toward the caregiver families, despite their efforts to provide the best care possible. The findings of the study revealed that unhealthy family relationships could not have resulted from the family's negligence to provide care. It is caused by unfamiliarity with the illness's behavior, the painful course of the illness, and a lack of understanding between the chronically ill and caregiver families. Misunderstanding usually produces more resentment, resulting in an uneasy social environment within the family.

Conclusion

According to the findings of this study, unfamiliarity with chronic illness and its treatments is a major challenge that families usually face when caring for the chronically ill members. As a result, caregiver families often develop chaotic emotion and behaviors such as anxiety, depression, confusion, hopelessness, and fear. Moreover, a lack of knowledge has an impact on familial relationships because of misunderstanding, usually between the patient and the rest of the family. The study emphasizes the importance of raising public awareness about the growing impact of chronic illness. As a result, it is recommended that, first, the growing problem of chronic disease and illness experiences be addressed in the public policy agenda; and, second, efforts be made to improve public knowledge about the growing impacts of chronic illness, allowing both the patient and the caregiver to mitigate illness-related perplexities.

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