



Courtesy stigma: A concealed consternation among caregivers of people affected by leprosy

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ABSTRACT

This study explored experiences of courtesy stigma among caregivers of people affected by leprosy. Using a qualitative research approach, twenty participants were purposively selected and in-depth interviews conducted. The interviews were audio-recorded, transcribed, and analyzed to identify emerging themes that addressed objectives of the study. The findings indicated that caregivers of people affected by leprosy experienced courtesy stigma. Evidence showed that fear of contagion underpinned caregivers' experiences, especially in employment and romantic relationships. In addition, participants adopted different strategies (disregarding, concealment, education, faith-based trust) to handle courtesy stigma. The findings demonstrate that psychosocial support and financial assistance to caregivers are necessary considerations for attainment of effective care for people affected by leprosy.

1. Introduction

The prevalence of leprosy, a chronic infectious disease, poses a public health concern as lasting impairments could develop if intervention is not provided on time or not implemented correctly (Bello et al., 2013). While improved healthcare and socioeconomic conditions in developed countries have drastically reduced the incidence of leprosy, in some developing countries like Ghana, cases of leprosy are reported yearly (Bello et al., 2013; Ghana Health Service, 2015; Ofosu and Bonsu, 2010). About 25% of people affected by leprosy in developing countries have some form of residual disability, which could affect their engagement in physical and socioeconomic activities, as well as predispose them to an altered role in society (Bello et al., 2013; Brouwers et al., 2011).

Physical disabilities caused by leprosy, as well as the impact of stigmatization and discrimination, continue to be key challenges (Deepak et al., 2013; World Health Organization, 2009). The effects of leprosy could remain for a very long time due to residual permanent impairments and progressive physical disability caused by the disease (Bello et al., 2013). In view of this, management of the condition requires lifestyle changes (Deepak et al., 2013; Innovative Care for Chronic Conditions, 2002) and the services of caregivers to assist with activities of daily living. This reflects the medical model of disability (i.e., disability caused by the disease), which is common in the field of leprosy. However, the United Nations Convention on the Rights of Persons with Disabilities adopts a social model of disability, which emphasizes that disability does not reside in individuals, but reflects

society's response to people's impairments (United Nations, n.d). This perspective on disability highlights the role of society in managing the disease.

As the burden of the disease consists mostly of impairments and disabilities of the feet and hands (Chingu et al., 2013; Van Brakel et al., 2012), people with severe deformities are likely to be restricted in terms of mobility and/or self-care. These conditions could have major impacts on the social, economic and psychological wellbeing of affected individuals and their caregivers, who are indispensable partners in the provision of care services for people with chronic health conditions. These caregivers are likely to have multiple responsibilities, including helping with daily chores, administering medication, providing transportation, preparing meals, assisting with hospital visits, managing finances, advocating for health care, and offering emotional support (Bevans and Sternberg, 2012).

Furthermore, people affected by leprosy are highly stigmatized and discriminated against due to concerns about the risks posed by the disease to the wider community. In an effort to decrease stigma associated with the disease, it has been renamed Hanson's disease. Nonetheless, leprosy is used in this paper because the term is commonly used in Ghana. For many years, leprosy has been regarded as the epithet of stigmatization given its negative image (Rafferty, 2005; Stevelink et al., 2011). As a result, leprosy related stigma is usually characterized by social rejection and stereotyped perceptions of people affected by the disease (Van Brakel et al., 2012). Generally, the stigma related to health conditions, such as leprosy is more damaging to affected people than the health condition itself as it impacts adversely on key areas of

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their lives, such as access to health and social welfare services, marriage, employment, educational opportunities, friendship, and self-esteem, which could result in emotional stress, anxiety and depression (Pescosolido et al., 2008; Tsutsumi et al., 2007).

The adverse effects of stigmatization on people affected by leprosy may be so intense that it could trickle down to their close associates, including family members and caregivers. While some leprosy-related stigma studies (e.g., Brouwers et al., 2011; Stevelink et al., 2011) have focused on people affected by the disease, there is rarity of literature on their caregivers. As argued by Hamlington et al. (2015) courtesy stigma has received less research attention and thus, seldom described in the literature. Further, MacRae (1999) opined that empirical work on courtesy stigma, as well as factors that influence its incidence is warranted because while Goffman (1963) explained in detail the processes by which courtesy stigma is acquired, not much was said about how it progresses.

Given that the challenges faced by stigmatized people spread among their close associates, (Goffman, 1963; Phillips et al., 2012), this study, which is part of a larger qualitative study, investigated courtesy stigma (also referred to as stigma-by-association, associative stigma or affiliate stigma) experiences among caregivers of people affected by leprosy. The objectives of this article were to identify (a) services provided by caregivers, (b) key areas that caregivers are stigmatized, and (c) caregivers' responses/handling of courtesy stigma. Such information would assist policy makers and professionals like social workers to better understand courtesy stigma. Besides, the study highlights the valuable role played by informal caregivers in providing care for people affected by leprosy. This underscores the importance of adhering to the principles of equity in care provision, non-discrimination and respect for human dignity and personhood.

In addition, this research is vital because those who are closely connected to people with stigmatized health conditions like leprosy are likely to be scorned, shunned and may experience social isolation in their families and communities. This could negatively impact areas of their lives, such as access to employment and marriage and therefore suggests the need to understand how caregivers of people affected by leprosy handle/respond to courtesy stigma. These notwithstanding, Sigelman et al. (1991) noted that there is a dearth of research to ascertain whether courtesy stigmatization does occur or to identify the contexts in which it likely occurs. Also, MacRae (1999) argued that courtesy stigma is a complicated issue that needs to be investigated. This paper therefore expands the literature beyond people affected by leprosy to include caregivers' experiences of courtesy stigma. It is hoped that as people become knowledgeable about courtesy stigma, they are more likely to accept caregivers of persons affected by leprosy.

1.1. Courtesy stigma and leprosy

The understandings derived from Goffman's (1963) pioneering study on stigma have been applied to an array of chronic illness conditions (MacRae, 1999). Stigma refers to a trait that is deeply devaluing (Goffman, 1963), and people possessing such trait are perceived as different from others in a way that is undesired and shameful (MacRae, 1999). Research evidence suggests that when people have stigmatized disease conditions, (leprosy in this case), members of their family experience courtesy stigma (Gray, 2002; Kayama and Haight, 2014). Courtesy or affiliate stigma occurs when a person experiences stigma because of his/her close association with another person with a stigmatizing feature and they are both devalued (Goffman, 1963; Hamlington et al., 2015). While individuals themselves do not have the mark, they are stigmatized because they live with, work with, or have close social relations with individuals or groups that are labelled (Pescosolido and Martin, 2015).

Goffman (1963) noted that the problems faced by stigmatized people spread out in waves of intensity among people they come into contact with. This could be applied to people affected by leprosy

(stigmatized people) and their caregivers (those they come into contact with). As stigma spreads from stigmatized individuals to their close associates, the latter are compelled to share some of the discredit (Goffman, 1963). Proving examples like the loyal spouse of the mental patient and the daughter of an ex-convict, Goffman argued that people in such situations are bound to share some of the disgrace of stigmatized people because they are related to them (1963, p., 30). Most often, family members of persons who have stigmatizing illnesses experience stigma due to their relationship with stigmatized people rather than through their own or personal features (Gray, 2002). Given the general fear of leprosy as a chronic infectious disease that is incurable (Briden and Maguire, 2013), courtesy stigma could be experienced by caregivers of people affected by leprosy as they may be perceived as risky.

Corrigan and Miller (2004) suggest that the two fundamental narratives that may lead to courtesy stigma are blame and contagion. Also, the nature of stigma associated with serious illnesses depends on some features like threats the illness represent to others (Dako-Gyeke et al., 2015; Fife and Wright, 2000). Since many people believe that persons who have been treated of leprosy may never be cured in a holistic way (Rafferty, 2005), experiences of courtesy stigma among caregivers of people affected by leprosy could persist for a long time. As contended by Ogden and Porter (1999) and Briden and Maguire (2013), the social and harmful consequences of leprosy are harsh. As such, some caregivers who experience courtesy stigma employ strategies (e.g., concealment, instrumental telling, neutralization, and preventive passing) to manage the situation (Schneider and Conrad, 1980; Jones et al., 1984). However, suppressing and reacting to courtesy stigma could lead to stressful demands on caregivers (Kayama and Haight, 2014).

As definitions of the situation are negotiated rather than given, affiliation with stigmatized individuals does not automatically result in courtesy stigma (MacRae, 1999). Thus, not all persons who are associated with stigmatized individuals would experience courtesy stigma. Similar to primary stigma, courtesy stigma, could contribute to constrained and negative social interactions in addition to judgment and blame from others (Phillips et al., 2012). Furthermore, perceptions of judgment and experiences of stigma by caregivers could contribute to reduced social support, isolation and health consequences, including increased stress and depression (Corrigan and Miller, 2004; Thomas, 2006). Additionally, courtesy stigma has been shown to place pressure on relationships between stigmatized individuals (e.g., those affected by leprosy) and their close associates, especially family members, which could impact on their capacity for care (Phillips et al., 2012).

Moreover, some researchers have reported varying degree of experiences of courtesy stigma since the relationship between courtesy stigma and health may be influenced by the nature of the relationship, stigma content and relative access to resources, such as income, education and protective social networks (Corrigan and Miller, 2004; Phillips et al., 2012). These theoretical perspectives are useful for this study, as the viewpoints provided explanations regarding why caregivers of people affected by disease related stigma may be affected by courtesy stigma. This underscores the need to extend the boundaries of leprosy research to include caregivers of people affected by the disease. Although extant research has shown that caring for people affected by leprosy is challenging, mainly due to the stigma associated with the disease, not much is known about how caregivers handle courtesy stigma, particularly in Ghana. This paper therefore contributes to filling the gap. The next sections present the methodology, findings, discussion, and finally conclusions and implications.

2. Methodology

2.1. Research design

This study was approved by the Ethics Committee for the Humanities (ECH) at the University of Ghana, Legon, Accra, Ghana. The research was drawn from a qualitative approach that used face-to-face

in-depth interviews to collect data. Given the paucity of research on courtesy stigma among care providers, an exploratory research design using open-ended in-depth interviews was appropriate for this study (Phillips et al., 2012), as it enabled the researchers to explore and understand the experiences of caregivers of people affected by leprosy. Participants were asked to describe their experiences regarding courtesy stigma.

2.2. Study site and recruitment of participants

The study was carried out at the Weija Leprosarium in the Greater Accra Region of Ghana for people who have been cured of leprosy. The facility is the largest among other Leprosaria located across the country: Ankaful, Ho, Nkanchina, Kokofu, Anindado and Ahontokrom. It has various amenities, including a clinic, offices for workers, apartments for people affected by leprosy and their families and a community center. The manager at the Leprosarium was contacted by the research team and permission was sought to visit the facility. Later, the manager invited the team to the Leprosarium in order to interact and build rapport with potential participants.

After an information sharing session by the research team, willing caregivers offered to participate by providing their contact details. Subsequently, appointments were scheduled for in-depth interviews (IDIs) with participants at their convenience. Participants were 18 years and above and were caregivers of people affected by leprosy. They consisted of both family members and non-family members and lived in apartments with people affected by leprosy at the Leprosarium. In total, twenty caregivers were recruited for the study and recruitment was continuous until saturation was attained when repetition of ideas and duplication of responses were observed. Guest et al. (2006) noted that data saturation can occur within the first twelve interviews and afterwards very little new phenomena are likely to emerge.

2.3. Demographic characteristics of participants

The participants (13 females and 7 males) were aged between 18 and 65 years with many of them being Christians (11). The other participants were Muslims (7) and Traditionalists (2). The highest educational background of the caregivers was as follows: post-secondary (4), senior high (1), primary (7), and there were eight participants who had no formal education. The ethnic background of participants was diverse: Hausa (7), Akan (6), Ga (2), Dagomba (3), and other (2). In terms of employment, fifteen participants were unemployed while five were employed at the time of the data collection.

2.4. Data collection and analysis procedures

The research was conducted from December 2014 to May 2015 and data were gathered through IDIs using a topic guide that included open-ended questions and related probes. This provided participants opportunity to speak privately with the researchers. The IDIs allowed the research team to explore the various ways participants experienced and dealt with courtesy stigma in their daily lives. Also, it offered participants opportunity to express themselves freely and permitted the researchers to probe participants' responses for clarification and discussion of emerging issues in detail. The topic guide, which was developed by the researchers, was first created in English and then translated into three Ghanaian languages (Twi, Hausa, and Ga) spoken by the caregivers.

The researchers explained the purpose of the study to participants before starting the interviews and they were individually informed of their right to withdraw their participation anytime they wished. Participation in the study was voluntary and potential participants were assured of confidentiality regarding information they provided. Verbal consent was sought from each participant and this was followed by a written informed consent. Participants completed a short demographic

questionnaire prior to commencement of the interviews. The interviews were conducted in English and Ghanaian languages. The language used with each participant was based on his/her preference.

With participants' permission, the IDIs were audio-recorded. Each interview was led by a researcher and supported by a research assistant who took notes. On the average, an interview lasted between 45 and 60 minutes and all took place at the Leprosarium. The researchers explained courtesy stigma to the caregivers and requested that they linked their experiences accordingly. Interviews included discussions on caregiving duties, remuneration, employment outside the Leprosarium, and courtesy stigma experiences. Also, participants were asked to describe how they responded to courtesy stigma.

Following the data collection, the audio recorder was replayed several times for the purpose of transcribing the data. The interviews conducted in Ghanaian languages were translated into English and some quotes were edited grammatically, however, it was ensured that the content was conserved. The meanings of participants' experiences were interpreted through repeated readings of the transcribed interviews (Lincoln and Guba, 1985). Themes and concepts repeated in the data were identified based on the objectives of the study. Themes that considered statements of meaning present in most of the data were extracted from the text. To ensure credibility of the findings, the transcriptions were supplemented with research assistants' field notes. Also, independently developed themes were interpreted and consensus reached through discussions with academic colleagues who had professional and/or academic experience in the field.

3. Findings

The findings of the study are presented in this section and organized under the following themes: provision of care services and remuneration, fear of contagion and courtesy stigma, access to employment and courtesy stigma, courtesy stigma and intimate relationships, and caregivers' responses/handling of courtesy stigma.

3.1. Provision of services and remuneration

The caregivers included in this study provided different kinds of services for the people affected by leprosy. Due to impairments in their hands and feet, many of the people affected by leprosy required assistance from caregivers. While some of the caregivers had close family relations with the people affected by leprosy, others did not. Also, many of the people affected by leprosy required assistance because they were elderly. Most often, Ghanaian families provide care for family members when they become dependent. A male family caregiver stated: *“if he could handle personal activities like taking a bath, I would assist him with other things, but that is not the case, I cannot leave him to be on his own”*. Furthermore, a female family caregiver echoed:

I live here with my mother-in-law. I assist with many activities because of her deformities. I have lived with her for almost 11 years now. I wash, cook and shop. I assist because no other family member is willing to help.

Also, included in the study were caregivers who were not family members of the people affected by leprosy. Sometimes, when family members are not available, non-family members are likely to step in and provide non-paid assistance to vulnerable persons, especially persons who are sick. Some caregivers have lived at the Leprosarium many years after the death of family members they assisted. A male non-family caregiver revealed: *“after the death of my father, my client requested that I stayed here to take care of him. I do almost everything for him: sweeping, shopping, cooking, fetching water, accompanying him to the hospital and others”*. Relatedly, a female non-family caregiver disclosed:

After my brother died twenty years ago, I stayed here to assist two elderly men. I have cared for them for four years. Their families do not visit them. I cook, clean, fetch water, go on errands and accompany them to

the hospital. They have difficulty moving around and using their fingers.

As the caregivers were responsible for the daily upkeep of the people affected by leprosy, they were asked whether they were paid for the services they rendered at the Leprosarium. The caregivers indicated that they did not receive money for the services they provided. In Ghana, most often, formal social welfare services are inadequate or unavailable and as such, families are responsible for taking care of their vulnerable members. Care of the vulnerable is connected to the family and this could explain why family caregivers were not paid for their services. For instance, a female family caregiver narrated:

I have lived with my grandmother for many years and learnt an artisan trade. Because of her condition, I had to stay and take care of her. She is very old so I cannot leave her. I do not get paid; we survive on the little money she receives from the government and other philanthropists. She has children, but they do not visit or send money.

Besides, given that the government does not provide much support to the poor in terms of jobs and housing, some non-family caregivers could care for people affected by leprosy without being paid because they may benefit indirectly. The benefits may include free accommodation and food as many of the caregivers live with their care recipients at the Leprosarium. In this regard, a female non-family caregiver revealed:

I assist these elderly people wholeheartedly without being paid. I am with them all the time because of their condition. If I leave, it will be difficult for them to prepare food, take medications, and do other things. I have a place to sleep, eat some of their food and sometimes they give me some money from the stipend they receive from the government. They have been neglected by their families.

Also, a non-family male caregiver who expected the government to pay caregivers explained:

I do not receive any money for assisting the old man, I provide the services for free. We survive on the little money he receives from the government. The government should pay us for the services we provide because taking care of them is difficult.

3.2. Fear of contagion and courtesy stigma

In view of the fact that leprosy is a contagious disease, many people are scared of being infected and as a result, avoid contact with people affected by leprosy, even if they were cured. Given their association with people affected by leprosy, caregivers are often perceived as risky as they may have been infected by the disease. Commenting on this issue, this is how a female family caregiver phrased it: *“because we take care of them and reside at the Leprosarium, people think we have the disease. We tell them caregivers do not have the disease, but they do not believe us and treat us like sick people”*. Other participants explained how caregivers were labelled due to their association with people affected by leprosy. These experiences could be embarrassing and limit opportunities available to caregivers as they are likely to be confined to the Leprosarium. A female family caregiver noted:

Many people are scared of the disease; they think the disease is not curable. It is difficult for us to make friends. I have to explain to people that my grandfather is cured and not at risk, but they hardly believe me. When we visit the nearby community, people say ‘these are the relatives of the lepers, we have to be careful else they will infect us with the disease’.

Some visitors to the Leprosarium also exhibited embarrassing behaviors or situations. Although the caregivers did not have the disease, they were likely to be devalued as a female non-family caregiver explained:

Many people who visit this Leprosarium become scared when they see

people affected by leprosy who have severe deformities. A thirsty male visitor refused water I offered him. He said he would buy bottled water later. I bought bottled water outside the Leprosarium for him, but he refused to take it. Even family members who visit us refuse to take water or food from us.

Furthermore, children who resided at the Leprosarium were stigmatized. Even though they were not primary caregivers of people affected by leprosy, some of them were mocked due to their social relations with affected persons. This could affect their development and wellbeing, especially their self-esteem. A female family caregiver shared her experience regarding negative perceptions people had about children who resided at the Leprosarium:

My friends and others insult me saying I would not be living with sick people if I was not sick. They ask if I am on medication because the disease is contagious. They use derogatory names for us and our children who have difficulty visiting the nearby community to play with other children, this is sad.

3.3. Access to employment and courtesy stigma

The caregivers included in this study emphasized the importance of employment. However, many of them were concerned about society's perception about them given their close association with people affected by leprosy. This affected their chances of getting jobs and could make life difficult since they would have to depend on the little money the people affected by leprosy receive from the government. A male non-family caregiver noted *“all I do is take care of him. It is difficult getting a job if you are associated with the Leprosarium because outsiders believe we all have leprosy”*. Similarly, a female family caregiver explained:

I am having difficulty finding a job. I started selling by the road side, people did not buy the items. Maybe, if I sell at a place very far from the Leprosarium where I am not known, people will buy my goods, but I cannot leave her for many hours.

Due to the anticipation of discrimination or rejection by potential employers, some caregivers did not seek for jobs. This could limit their chances of taking advantage of opportunities outside of the Leprosarium. A male non-family caregiver who anticipated being stigmatized should he attempt looking for a job explained:

I do not have skills to work in the formal sector. I am interested in working as a part-time cleaner to enable me take care of my grandfather. Employers will not hire me because of the fear that I have the disease. I cannot lie about my residence so I have decided not to look for a job. Although I need money, nobody will offer me a job.

Considering caregiving as a full time job, some caregivers did not seek other jobs. Providing daily care could be tedious, especially if care recipients have limited use of their hands and feet. A female family caregiver noted:

I do not intend looking for a job because I consider this work as full time. It is unfortunate that what we do is not appreciated, hence we do not get paid. I am convinced that no employer will hire me because of my association with the Leprosarium. Even if I engage in petty trading, nobody will buy from me.

While several of the caregivers did not have jobs, others engaged in jobs outside the Leprosarium to support themselves and the people affected by leprosy. The few caregivers who had jobs outside the Leprosarium experienced some challenges as they had to combine caregiving responsibilities with other jobs. A male non-family caregiver noted:

I have a part-time job, but anytime my care recipient falls sick, I seek permission to accompany him to the hospital. I have to be with him

whenever he is hospitalized. Such situations affect my work and efforts at securing a permanent job.

In addition, some caregivers who worked outside of the Leprosarium were fired when their association with people affected by leprosy became known to their employers. A male family caregiver who was formerly employed, but was fired because of his association with the Leprosarium explained:

I had a security job and when my employer got to know that I lived at the Leprosarium, he asked if I had ever had leprosy and I said no. He asked whether I was not scared residing at the Leprosarium. He started complaining about my work and his attitude towards me changed for the worse. He did not want me to get closer to him and eventually fired me. Since then, I do not feel inclined looking for a job.

3.4. Courtesy stigma and intimate relationships

Usually, caregivers of people affected by leprosy find it difficult interacting with people outside the Leprosarium due to society's misconceptions and beliefs about the disease. Many people perceive the disease as being caused by supernatural forces and this could serve as a barrier to finding suitable partners. Some caregivers explained how they found it difficult dating as a female family caregiver noted: *“a man I dated insisted I moved out of this Leprosarium to avoid becoming infected. He was scared of the disease and always thought I had the disease. He broke up with me after few months of dating.”* Likewise, a non-family female caregiver shared her experience:

Many men perceive us as being infected with leprosy and therefore shun us. They do not want to get close to us. Despite our assurances that people living at the Leprosarium are cured. We are treated as if other women are better than us, but that is not the case.

The fear of rejection by potential intimate partners prevented some caregivers from dating. This suggests that the caregivers validated the negative beliefs, myths and shame that are usually linked with the disease. A non-family male caregiver who anticipated that he would be rejected by ladies should he attempt proposing to them had this to say:

I am not shy of women. I am being careful because I know that ladies are not interested in dating men who reside at a Leprosarium. Even if I propose to a lady, I do not think she will visit me or inform her friends that I reside at a Leprosarium.

Other caregivers indicated that they did not have plans of engaging in intimate relationships. Their concern was how people would relate to them if they got to know they resided at the Leprosarium and also perceived them as cursed. As such, a female family caregiver noted:

I do not have plans of dating a man. I am being careful because if I am in a relationship, I cannot hide my residence from him because when it gets to the time for us to get married, I am not sure his family would accept to have the marriage ceremony at the Leprosarium. They believe leprosy is a spiritual disease and affected families are cursed.

3.5. Caregivers' responses/handling of courtesy stigma

The caregivers described various ways they responded to or handled courtesy stigma. Among these were ignoring comments made by people, concealment, educating people about leprosy and faith-based trust. In their attempt to refuse being victims of courtesy stigma, some caregivers snubbed comments made by people. A female non-family caregiver noted: *“horrible things are said about me because of my relationship with people affected by leprosy. I disregard what people say, else I would be compelled to leave this Leprosarium.”* Also, a female family caregiver revealed:

I do not care about what people say. I have decided to assist these people.

We cannot tell when someone will fall sick so we do not have to look down on sick people. It is all about your willingness to assist people who are in need.

Concealment was another strategy used by some caregivers to manage courtesy stigma. Given that their association with persons affected by leprosy could contribute to constrained and undesirable social interactions, as well as judgment and condemnation from others, some caregivers preferred not to disclose their identity. A female family caregiver asserted:

In order to avoid being treated badly by others, I have decided that if I go out, I will not reveal that I live with cured lepers. The way I carry myself, it is hardly known that I reside at the Leprosarium.

For other caregivers, having faith in God helped them to handle courtesy stigma. As people view leprosy as a spiritual disease, it is possible some caregivers would consider this strategy. The following are excerpts from a male non-family and female family caregivers respectively:

Although people make mockery of us, I am still taking care of cured lepers because I believe in God who will intervene on my behalf. Sickness is from God so God blesses people who take care of the sick. Sickness is not bought; if it is bound to happen, it will happen.

It is difficult living in this Leprosarium. God is my hope so I do not pay attention to what people say about me. I try to be patient because if I decide to react to negative behaviors of others, life will be difficult for me.

Caregivers also reported of educating people due to lack of understanding and myths associated with the disease. Presumably, the more knowledgeable people become, the greater the possibility that they would accept the caregivers. A female family caregiver asserted:

Even at church, people did not interact with me because I reside at the Leprosarium. The situation was unbearable so I had to educate them by emphasizing that the disease was curable. I informed them that before people were allowed to reside at the Leprosarium, they had to show a health certificate confirming they were cured.

Also, a male non-family caregiver explained:

I try to reduce the extent to which people mistreat me by educating them about the disease. I tell them it is curable so they should consider leprosy as any other sickness. People are involved in accidents and their legs and hands are amputated and have deformities like people affected by leprosy with deformities. Public education about leprosy is important.

3.6. Discussion of findings

This study explored courtesy stigma experiences among caregivers of people affected by leprosy in Accra, Ghana. The findings indicated that the caregivers provided various types of services (e.g., daily chores, administering medications, preparing meals, and helping with hospital visits) without receiving payment. Given that many of the people affected by leprosy were elderly and had impairments mainly in their hands and feet, caregivers were responsible for care recipients' daily household activities. Caregivers are key partners in the provision of care services for people with chronic health conditions (Bevans and Sternberg, 2012), such as permanent impairments caused by leprosy (Bello et al., 2013).

Many caregivers included in this study, reported of courtesy stigma experiences from people due to fear of contagion. Being a contagious disease, many people are scared of being infected by leprosy and as a result, spurn those who are affiliated with them even if they are cured. This could be an obstacle to people's willingness to provide support for persons affected by leprosy. Experiences of stigma by caregivers may lead to isolation and reduced social support (Phillips et al., 2012). In addition, courtesy stigma could place pressure on relationships between

stigmatized individuals and their close associates, particularly family members, which could adversely affect their capacity for care (Phillips et al., 2012), as well as hinder their participation in social and economic activities, such as employment.

Caregivers of people affected by leprosy are often subjected to devaluation through suspicion of having the disease and this could serve as a barrier to finding jobs. While many of the caregivers included in this study did not have jobs, they were also not paid for the services they rendered at the Leprosarium. Compounding the situation was the fact that the few caregivers who had jobs were fired by their employers upon hearing that they were associated with people affected by leprosy. Some scholars have observed that the mere association with people who had been blacklisted reduced their chances of finding employment (Pontikes et al., 2010). Surprisingly, the medical field is not spared this menace; within the medical prestige hierarchy, psychiatrists are confronted with stigmatizing actions (Pescosolido and Martin, 2015).

Anticipating that they would be stigmatized or discriminated against if they engaged in income earning activities, such as petty trading, some caregivers did not make attempts at engaging in income generating activities. This is a self-limiting behavior that could have a negative impact on the lives of caregivers (Thornicroft et al., 2009). Irrespective of how courtesy stigma is experienced, it can expose caregivers to rejection in other interpersonal areas, such as intimate relationships. Courtesy stigma played a key role in caregivers' limited opportunities for intimate relationships. Restricted social interaction could be a barrier to developing and sustaining intimate relationships as found among participants of this study. Also, perceived contagion could imperil caregivers' ability to negotiate fundamental social prospects, such as marriage (Jones et al., 1984; Stangor and Crandall, 2003; Yang et al., 2013).

Although to the best of my knowledge, this issue has not been much researched, this finding is not startling because apart from leprosy related disabilities, courtesy stigma experiences of caregivers may be similar to that of people affected by leprosy and this include intimate relationships. Caregivers of stigmatized people may themselves experience the same consequences of the stigma (Carlisle, 2001). The fear of judgement and rejection could result in further isolation, hence, limiting their support networks when both emotional and physical help is desired (Dako-Gyeke and Baffour, 2016; Goffman, 1963). The situation becomes worsened when stigmatized people begin to internalize or redefine themselves in ways, which arise from society's image of them, and then view themselves from the other's perspective and apply a negative evaluation to their situation (Carlisle, 2001). Although some caregivers may adopt this strategy to manage the situation, others may respond to courtesy stigma differently.

As social isolation is an obvious everyday aspect of courtesy stigma, in order to continue assisting people affected by leprosy, caregivers included in this study utilized various strategies to respond to the situation. In the case of leprosy, courtesy stigma is likely to increase for caregivers of affected people with severe disabilities. As argued by some scholars, the stigma potential of a disease condition is greater when it is more visible (Crocker et al., 1993; Jones et al., 1984). The findings of this study confirm earlier works (e.g., Jones et al., 1984; Schneider and Conrad, 1980), which reported that caregivers of people affected by stigmatized health conditions adopted techniques, such as disregarding, concealment and education, to manage courtesy stigma. Interestingly, some caregivers in this study indicated that they handled courtesy stigma by faith-based trust - trusting in God.

Due to the negative meanings, misconceptions and spiritual beliefs that are usually linked to chronic infectious diseases, as well as those affected (Goffman, 1963; Lusli et al., 2015), it is possible some people, including caregivers of persons affected by leprosy would attach a spiritual dimension to the etiology and management of the disease and its associated stigma. A limitation of this study is that participants did not include caregivers of people affected by leprosy who did not reside at the Leprosarium. Besides, the study focused on caregivers in one

facility and therefore the findings cannot be generalized. However, the findings offer evidence regarding courtesy stigma experiences of caregivers of people affected by leprosy at the Weija Leprosarium. Also, the findings could be applied to similar situations (Lincoln and Guba, 1985), such as caregivers in other leprosaria.

4. Conclusions and implications

In conclusion, the findings of this study demonstrate that caregivers are key partners in the provision of services for people affected by leprosy due to their disabilities, which usually place limitations on their mobility and self-care. The caregivers experienced courtesy stigma, which adversely affected their efforts at securing jobs and engaging in intimate relationships with implications for their finances and psychosocial wellbeing. Unquestionably, the fear of contagion was the main reason why the caregivers experienced courtesy stigma and this was mainly due to the myths associated with the cause and treatment of the disease. This could lead to social isolation and in consequence, many of the caregivers are likely to be confined to the Leprosarium with little opportunity for social participation outside of the facility. The findings suggest the need for psychosocial counselling and financial assistance for caregivers of people affected by leprosy. Additionally, it would be useful to educate the general public more about leprosy, through effective awareness raising campaigns.

Furthermore, evidence indicates that caregivers who participated in this study adopted different strategies to handle courtesy stigma. Among these were disregarding, concealment and education as also emphasized by scholars like MacRae (1999). The importance of this study partly lies in the finding that in addition, some caregivers dealt with courtesy stigma by adopting faith-based strategy - trusting in God. Clearly, this shows that strategies utilized by participants in the current study go beyond those reported in the extant literature, which offers an opportunity for researchers and helping professionals, especially social workers, to investigate and understand the complex nature of courtesy stigma and how it is managed. This is crucial as there is not much research on courtesy stigma (MacRae, 1999; Phillips et al., 2012). Moreover, while designing support programs for people affected by leprosy, the concealed needs of their caregivers should be considered and addressed in order to ensure improved care and wellbeing of both caregivers and their care recipients.

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