



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

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