

Mehboobun Nahar Milky

LONELINESS AND CAREGIVING: EXPERIENCE OF LONELINESS AMONG FAMILY CAREGIVERS OF CANCER PATIENTS

Abstract

Cancer diagnosis and its treatments have a profound impact on cancer patients' families in multiple ways. Caring for a family member diagnosed with cancer is a complex, extensive and arduous task that makes a caregiver vulnerable to psychological distress. This study aims to gain insights into the aspects of loneliness incurred while caring for a cancer patient within the family. Though several studies have been conducted to understand psychosocial distress among caregivers but in the context of Indian populace, it has not been well explored. In-depth and semi-structured interviews with eight caregivers of cancer patients were conducted in Kolkata, West Bengal, India. Three major themes were identified: perception and tasks of caregiving, feelings of loneliness, and enduring illness. Findings from this study offer an account of the participants' perceptions of loneliness and its consequences among the caregivers of cancer patients, and their strategy to gain resilience towards it. Caregivers' experiences of loneliness often contributed to adverse effects on their emotional, social, and physical wellbeing. The unique individual experiences of cancer caregivers require an in-depth understanding of how caregiving is subjective and how loneliness affects the wellbeing of both caregivers and patients diagnosed with cancer.

Keywords: *Cancer, Caregivers, Caregiving, Coping, Loneliness*

Introduction

Today's estimates of cancer are alarming: as per the estimate, every year more than 12 million people throughout the world are diagnosed with cancer (Hesketh, 2013; Jemal, Torre, Soerjomataram, & Bray, 2019). Recent statistics of cancer incidences and mortality indicates that around 9.6 million cancer deaths and new cases of cancer amounting to more than 18.1 million worldwide were reported in 2018 (Jemal, Torre, Soerjomataram, & Bray, 2019). In the Indian context, studies show that the cancer estimates for the country are disconcerting and it is viewed as one of the primary reasons behind

MEHBOOBUN NAHAR MILKY, School of Humanities and Social Sciences, National Institute of Science Education and Research, HBNI, Bhubaneswar, Odisha, India, Email id: mehboobun.milky@niser.ac.in

premature deaths (Murthy, Chaudhry, & Rath, 2008; National Cancer Registry Programme, 2013; Jemal, Torre, Soerjomataram, & Bray, 2019). According to Jain (2018), there are approximately 2.25 million people with cancer in India, and every year there is an addition of about 700000 new registered cases. Takiar, Nadayil, & Nandakumar (2010) points out that more than 80% of cancer cases in the country are in advanced stages, and palliative care is essential towards improving their quality of life and family members of the patients play a vital role in providing care. Ferlay et al., (2013) has estimated that the total number of individuals in requirement of palliative care in India is about 5.4 million per year.

A diagnosis of cancer, and the associated threats of mortality often affect one's life (Williams, 1984). For not just the patients, but their caregivers¹ as well, cancer is an experience that can be seen as life-changing, which alters their life course forever. Though cancer happens to individuals, it affects many others since an individual is not an island onto himself/ herself; the individual is a part of a family and a society. Thus, cancer alters the lives of a set of people and not just the patient, forever.

It is pertinent to note that the moment of diagnosis is the beginning of an endless ordeal and a struggle for survival for both the cancer patient and the caregiver. At first, the focus is to survive the difficult disease and the gruelling treatment regime. And after the treatment period is over, the attempt is to accept the 'new normal' and adapt accordingly (Alfano & Rowland, 2009, p. 425). It is not just adverse physical effects, the cancer patients as well their families often go through financial stress and psychological issues such as depression, loneliness and post-traumatic symptoms (Tesauro, Rowland, & Lustig, 2002). Cancer and its treatment impact both the quality of life and relationships, both familial and societal (Northouse, Mood, Templin, Mellon, & George, 2000; Mellon, Northouse, & Weiss, 2006; Morris, Grant, & Lynch, 2007; Wagner, Das, Bigatti, & Storniolo, 2011).

An instance of how cancer's impact is found not just on the patient, but the caregiver as well can be found in a study by Edwards and Clarke (2004) which stated that the patients and their family caregivers undergo similar levels of anxiety and depression. In fact, a qualitative study by Mellon (2002) found that it is the caregivers who fear the recurrence of cancer more than the patients themselves, underlying how caregivers may be even more traumatized than the patients, at times. Physical sequelae of cancer does not remain confined to the patient, as the caregivers face physical and psychological impacts, as they too experience fatigue, physical and emotional burden, change in their normative roles, etc. (Jensen & Given, 1993; Wagner, Das, Bigatti, & Storniolo, 2011). A study by Jensen & Given (1993) conducted on 248 caregivers found that varied levels of fatigue were experienced by all of them, with a significant number showing signs of severe fatigue.

Moreover, cancer caregivers are often found grappling with depression, health issues, and future uncertainties (Institute of Medicine of the National Academies, 2008). To compound the matters, it is found that such physical and socio-psychological issues continue long after the treatment. A qualitative study by Hodgkinson and colleagues on cancer survivors found that there were several unmet needs even after the cancer treatment had ended (Hodgkinson, Butow, Hobbs, & Wain, 2007). Sometimes, the caregiving process can be so difficult as to elicit serious considerations of morbidity and may even contribute to mortality (Schulz & Beach, 1999).

Cancer diagnosis is a major turning point in a person's life where the normalcy of the life that he/she led till then is severely disrupted. Hardly does one find oneself prepared to face this sudden and irreversible disruption. And it is not just the cancer patient, the life of the caregiver too is adversely impacted with regards to their social and personal relationships as well as work schedule, due to the stressful and time-consuming nature of caring for a critically ill person (Rokach & Sha'ked, 2013). This usually leads to manifestation of psychosocial issues for the caregivers, such as loneliness (Rainer & McMurry, 2002).

Loneliness is a universal experience irrespective of one's gender, race, age, social or economic status, and it is something that may either be for a specific period or be felt persistently (Rokach & Sha'ked, 2013). Loneliness is defined as "the unpleasant experience that occurs when a person's network of social relations is deficient in some important way, either quantitatively or qualitatively" (Perlman & Peplau, 1981, p. 31). Weiss (1973) proposes two kinds of loneliness based on the type of social deficit, i.e., emotional loneliness and social loneliness. An absence of intimate relationships results in emotional loneliness, and social loneliness occurs when one is unable to integrate adequately with the social network such as in the work place, neighbourhood, friends, community, etc. There are studies which indicate that lonely people are more prone to facing financial stress, lack of friends and even domestic violence (Rokach & Sha'ked, 2013). In comparison to other people, lonely individuals tend to be more self-absorbed and find it difficult to connect with others effectively in a social set up, often destroying one's relationships (Heinrich & Gullone, 2006). One's cognitive features such as attention span, logical thinking, memory, etc. may get negatively affected by loneliness (Cacioppo & Hawkley, 2009) and this may result in serious psychological issues such as depression and unhealthy self-deprecation. (Rubenstein & Shaver, 1982). According to Theeke (2009), acute and continued loneliness may result in poor health, sleep disorders, hypertension, lack of intimacy in conjugal relationships, psychological distress and may even lead to dementia.

Though there exists some research on the kind of effects that caregiving has on the physical and mental health of the caregivers, much of the research on caregiving, however, is focused on two issues, i.e., stress and coping

strategies (Folkman & Moskowitz, 2004; Pearlin, Mullan, Semple, & Skaff, 1990). As per the existing research, family caregivers, especially elderly spouses, are the most affected by caregiving in terms of their physical and mental health issues (Ostwald, 2009). The study by Schulz and Beach (1999) identified the severity of the risk of a hastened death for the older spouse caregivers when compared to the others of the same age. This in no way should be construed as the lack of risk for non-elderly family caregivers; it's just that the severity is much greater for the elderly, and it is instructive to note that the overall context in which caregiving is done, contributes majorly to such a situation. The study of Schulz, et al., (1997) identified a few major factors in the increased level of stress among family caregivers. According to them, if the caregiver and the patient shared a close and intimate relationship before the diagnosis, then that would put greater stress on the caregiver in the process of caregiving. Moreover, if the patient's level of dependency on the caregiver is greater, greater would be the stress on the caregiver as well. A lack of social support is another contributing factor in increased levels of stress on the caregiver. All of this contribute towards a sense of acute helplessness and results in profound loneliness in the caregiver. The fact that almost all of the family caregivers are non-professional carers, who learn on the job the different aspects of caregiving, such as assisting the patient in his/ her daily chores, ensuring proper prescribed medication is done on time, dealing with possible side-effects, etc., makes their job a stressful and lonely affair. Lack of confidence in how well they are able to carry out their duty makes them feel a sense of guilt as well, and the fact that they rarely get to share these uncertainties and intimate problems with others, makes them more self-absorbed and that too has an adverse impact on their mental wellbeing, generating in them feelings of sadness, frustration and helplessness (Ojeda, et al., 2014). The study by Ekwall et al. (2005) highlighted the aspect of social exclusion experienced by family caregivers. They stressed on the fact that this kind of social isolation, often an involuntary one, contributes greatly to their loneliness.

It can be surmised from the existing research on caregiving and its impact on the caregivers that most of the family caregivers experience feelings of burden, sadness, helplessness, a sense of guilt, lack of social engagement, and all this results in them becoming more self-absorbed, which makes their sense of loneliness a more acutely felt experience. Lack of social support or the perceived lack of it has been identified by many researchers as a major contributing factor to the caregivers' sense of distress (Goldstein, Atkins, Landau, Brown, & Leigh, 2006), their lack of happiness in conjugal relationship (O'Connor, McCabe, & Firth, 2008) and the much-compromised quality of life (Chiò, et al., 2004). This lack of social support often tends to be an almost irreversible phenomenon as the caregivers, even if they do their best, fail to reconnect with their old acquaintances and relatives, because it is they who stop visiting the family of the cancer patient for fear of being burdened as well (Rokach & Sha'ked, 2013), and hence recuperating from such an ordeal becomes

an extremely arduous task for the caregivers.

Recently, some studies have been undertaken on cancer patients and their caregivers in India. However, only a few of these studies discuss the profound psychosocial impact of cancer on the patients and their family members (Arunachalam, Thirumoorthy, Devi, & Thennarasu, 2011; Chaturvedi, Shenoy, Prasad, Senthilnathan, & Premalath, 1996; Jagannathan & Juvva, 2009; Chawak, Chittam, Butow, & Huilgol, 2020). Goswami & Gupta (2018) observed that, sometimes while providing care to the terminally ill patients in India, the caregivers neglect their own needs leading to their own psychological and financial stress. Their study found that, family caregivers are generally females who are actively involved in the process of care giving, and are the worst sufferers. However, there is a dearth of research on the kind of negative effects that caregiving has on the physical and mental health of the caregivers in India. It is against this backdrop this study is undertaken where I intend to understand how the process of caregiving leads to the feelings of loneliness, its consequences among the participants and the strategies used to cope with loneliness.

Theoretical Framework: Biographical disruption and Loneliness

The theory of biographical disruption, introduced by Michael Bury in 1982, is a seminal concept that tries to encapsulate the catastrophic effect of a diagnosis of chronic illness among individuals. Biographical disruption has been used as both a descriptor and as an explanatory tool to understand how people respond to and adapt to chronic illness. In his work regarding chronic illness, Bury discussed chronic illness as “the kind of experience where the structures of everyday life and the forms of knowledge which underpins them are disrupted” (Bury, 1982, p. 169). He described three aspects of biographical disruption. First, illness interrupts the body, social roles and the social world through “the disruption of taken-for-granted assumptions and behaviours” (Bury, 1982). Second, chronic illness upsets self-identity, affecting one’s individual biography (Charmaz, 1983; Charmaz, 1994; Charmaz, 1995). And third, the way in which people react to disruption involves “the mobilisation of resources in facing an altered situation” (Bury, 1982, p. 169). However, biographical disruption has not been explicit in research on caregivers of individuals with chronic illness and on loneliness, the concept resonates with several research findings. By using the aspects of Bury’s biographical disruption, research can be reinterpreted to suggest that this might be a helpful concept. Numerous events and alterations in one’s life due to the tasks of caregiving can lead to major changes in the structure and functions of everyday life, that may trigger loneliness, which may have the potential to hamper the life course, leaving people searching for personal meaning in order to make sense of the altered situation. Similarly, loneliness can affect one’s idea about self, their assumptions of the social world and the social relations they maintain (Cardono, 2010).

Additionally, events such as chronic illness that induces loneliness may compel an individual to make sense of their changed circumstances and reconstruct a biography that reflects present, past and future. Interpretations of research findings above suggests the efficiency of utilising biographical disruption as a lens through which to view loneliness. However, past research has not meticulously used this stance. This article attempts to use the concept of biographical disruption in understanding loneliness among the caregivers while caring for a chronically ill family member and see whether there are incidences of biographical flow or not. This study, with the knowledge about the state of loneliness during a caregiving process for a family member with cancer may elucidate information regarding types of specific interventions that might be beneficial in overcoming loneliness.

Method

Study design

This qualitative enquiry employed an ethnographic approach to explore the varied experiences of loneliness among the family caregivers of patients with cancer. Through ethnography, one can have an understanding about the daily processes, routines and perspectives of the participants resulting in a 'thick description' (Geertz, 1973) from the participants about the phenomenon under study. Along with observation, interviews were used for collecting data. Face-to-face interviews provided in-depth description where the participants shared their experiences of being a caregiver to a cancer patient in their family. The interviews were semi-structured, where an interview with open ended questions guided the interviewing process. The participants chose the time and location for the interview and the average duration for each interview was about 70 minutes. The study was carried out in Kolkata, West Bengal. During the interview, empathic probing was used to elicit the participants to provide a clear version of their experiences. The entire interview was transcribed verbatim for further analysis.

Participants

The participants were selected through purposive sampling. The inclusion criteria were: a) family member who is considered by the patient as most involved with her/his care, b) patient has to be 18 years or older and currently undergoing treatment, c) ability to interact in Bangla, Hindi or English, d) consent and willingness to participate in the study. A total of eight participants were recruited in the study of which seven were male and one female. The participants were Bengali, yet culturally diverse, geographically scattered from both urban and rural settings with varying socio-economic status. The average age of the participants was 41.6 years. Two participants were caring for patients with breast cancer, two with oral cancer, one each

with prostate, abdominal, liver and stomach. The time since the diagnosis of the cancer for the patients ranged from two years to ten years.

Data Analysis

After repeated reading, an extensive understanding of the interview statements was obtained. The interview contents were transcribed verbatim to acquire insider's perspectives about the experiences of family caregivers of cancer patients. The transcripts were then subjected to thematic analysis. Line-by-line review of codes within the transcripts were done. The meaning of each statement was analysed and the analysis of similarities and differences within the transcript codes were done. The similarities were organised and summarised from the meanings to develop category themes. The rigor of the qualitative data analysis was achieved through prolonged engagement with the data and the use of memo developed during the iterative analytic process. The codes were also discussed with peers, who had experience in qualitative analysis, to ensure validity. The results shown are based on this iterative process.

Results

The results of this study are discussed through three themes: perception and tasks of caregiving, feelings of loneliness, and enduring loneliness. Several subthemes were identified amongst these themes, which are as follows:

1. Perception and Tasks of caregiving: caregiving as responsibility/ duty, various tasks of caregiving
2. Feelings of Loneliness: overwhelmed with care work, disconnected, lack of guidance, poor understanding by close people, reduced private space, declining social relations, helplessness and powerlessness
3. Enduring loneliness: acceptance of reality, futility in fighting, optimistic thinking, understanding relationship, spirituality

Theme 1: Perception and tasks of caregiving

Caring as responsibility / duty: Caring for a cancer patient within the family is difficult. For most of the participants, whether spouse, child or sibling, caregiving for a cancer patient was about doing everything possible to prolong the patient's life and ease their condition. A few participants who were overwhelmed by the tasks of caring considered it as a 'responsibility' or a 'duty' towards the patient that comes with the relationship that they share. Spouses viewed marriage as encompassing of one's carer role, an expected part of their relationship, whether a mutual understanding or a religious obligation. Likewise, many children with a cancer parent considered it as an expected responsibility towards their parent. K3 said-

I am the only son of my parents... my father's treatment, his care is mine... my father's responsibility is upon me.

Various Tasks of Caregiving: From the transcripts, it was clearly understood that the participants were often struggling with life while performing care work. Care work involved various tasks of caring such as activities of daily life, household chores, symptom management, finances and needs of other members of the family. Cancer work influenced other day-to-day activities, asking for more efforts in accomplishment of those works.

I have to manage everything - my life as well as taking care of everyone, my father, mother and sister... I have to balance both the household and other works. (K5)

I manage everything, from cooking, cleaning, shopping and my business as well. Initially it was difficult, but now, over the time, I have learnt how to manage. I can manage now. (K6)

Theme 2: Feelings of loneliness

This theme describes the perceived circumstances leading to the feeling of loneliness among the family caregivers of the cancer patients. In the following section, this theme is divided into several sub themes.

Overwhelmed with care work: This subtheme focuses on the aspects that a caregiver has to face on a daily basis while caring for a cancer patient and how it contributes to their loneliness. Generally, the major task of caring involves attending to the symptoms and treatment related issues, which is often considered as unending, difficult and stressful by most of the participants. The extreme difficulties involved in carefully attending to the various physical ailments faced by the patient become an arduous task, especially in the initial days of care when one is not used to the process. With time, even though the carers get used to the process, it still takes a heavy toll on their own physical and mental conditions, as it takes up a huge chunk of time disrupting their daily routine.

When you have someone like this at home, you have to care for them round the clock... there is no rest; forget about rest, I don't remember when was the last time that I had proper peaceful sleep. I have to clean the overnight-accumulated pus from his mouth. It's so smelly, like something is rotting inside, or perhaps worse than that, and it takes time... lots of time; I do it very slowly. I have to wipe it clean and then, there is blood. Blood oozes out from there [orifice]. Taking care of him is very difficult, I have to be careful. (K3)

Apart from managing the symptoms, the participants have undertaken various other tasks on a daily basis. These tasks were regarded as hard,

strenuous and demanding. Many participants took care of household work and the needs of other family members.

I have to look after everything... I have to balance both the household and other works majorly. (K6)

I manage everything; cooking, cleaning, shopping and my business as well. Initially, it is difficult; I have learnt how to handle it. But frankly saying, I get too tired after all this. It's tough. (K4)

Disconnected: The task of caregiving has affected other facets of the participants' life. Participants pursuing formal education have to face greater difficulties while tending their ailing parent. A few of them have to drop their education in order to efficiently provide care, especially in those cases where the concerned parent was the sole earning member in the family and used to manage the household.

Before this, my life was good, it was as perfect as one can dream of... I was studying, focusing on getting a job, my father was managing the house hold and the farm, but now everything is gone. I have to leave my education so that I can sustain our family and take care of my father. (K3)

Lack of guidance: All the caregivers participating in this study described how caring for a cancer patient is difficult and tasking and how it could have been easier if someone was available to help them out. A few participants mentioned about the need of guidance while caring for a family member diagnosed with cancer at some point of time. K1 said:

I was hoping if someone could show me physically how to do it, then it would have been easier or perhaps someone could do it ... Once I have hurt her unknowingly while dressing her wound... it is when I feel most lonely and desperately wish someone was there to guide me and help me out.

I have to change his shirts and towels, he is always leaking from his mouth... clean them... dry them properly in sun, give him a bath, clean his discharges. I have to look after so many other things along with his [father] care and there is no one to help me, no one to guide me and tell me which technique is easier. I have to do it all by myself. (K3)

Poor understanding by close people: A few participants mentioned that they feel lonely when people around them are having difficulties in understanding what the participants are trying to convey and what they are going through.

I felt lonely and sad when I told my friend that it is difficult for me to go out as I have to be with my father. (K3)

The feeling of being understood is important when you are going through a crisis like this. (K1)

Reduced private space: Experiences of loneliness among the family caregivers was often seen to be linked with the constraints due to the tasks of caregiving. A few participants discussed about how their daily life was characterised by reduced freedom to have and manage their time and choice of space, by a lack of spontaneity, and with limited scope of being away from concerns. The needs of the patient were the top priority and a constant pre-occupation.

I don't have time for myself... it's all about her care, either am taking care of her or managing the work. I do feel burdened with all this, but I can't do anything. (K6)

Sometimes when I am hanging out with friends, I smoke. And now I don't get the time to be with them. (K3)

A break would be good... sometimes I desperately want a break from all this...where I don't have to wake up early, do the household chores, won't have to worry about anything- her [patient] health, medication or her food... just a bit of time for myself where I can just sleep and relax or perhaps read a book or watch a football match. (K5)

Declining social relations: This subtheme focuses on the experiences of alienation from the relations, whether friendship or kinship ties, that the caregivers maintained earlier. A few participants talked about the losses and deprivations they faced with respect to their close relationships. The rearrangement of these relationships on both practical and emotional state due to their circumstances were sometimes perceived to heighten their loneliness.

Friends! When you have a situation like this, everyone leaves you, even your relatives. I felt really bad; I was like a son to them and look how they are behaving, just because I need money and some help - that too for my father's treatment! (K3).

Soon after the diagnosis, our relatives drifted away. They severed all connections with us. We are on our own. (K2)

Helplessness and powerlessness: A few participants discussed loneliness in the context of an overwhelming sense of helplessness when they could get no help from people at the time of need, especially when they faced a difficult situation which was not easy to manage on their own. On these occasions, loneliness was marked by a feeling of powerlessness where the caregivers felt they neither had control over their situation nor did they know how to deal with it efficiently. This absence of help and support from others during a time of need / crisis made them perceive their caregiving role as a solitary activity

where one had to fend for oneself, and this perception coming out of their lived experience led them to a feeling of profound loneliness.

There are so many things where I can use a bit of help, but unfortunately, we don't have any scope of that. (K4)

I was hoping if someone could show me physically how to do it; it would be easier or perhaps someone could do it, anyone! Things are getting worse day by day. I have to manage everything on my own. I feel so helpless! (K1)

This kind of lack of help from anyone made the caregivers feel solely responsible in carrying out their duty, and the enormity of this responsibility accompanied by the feeling of loneliness weighed heavily on their shoulders. For many of them, it was not even a matter of someone else sharing their responsibility, but even a semblance of help, however symbolic in nature, may not have physically eased their burden, but at least made them feel that they were not alone, and this would have gone a long way in assuaging their sense of helplessness and loneliness. Additionally, the thought about losing their loved ones due to untimely death has heightened the feelings of loneliness and helplessness among the a few participants

I am at the brink of losing everything. She [patient] is here, but just in flesh and blood. Then after a few months, I will be completely alone, with no one beside me. I will be stuck in my house, waiting for each day to pass and yes, I have to wait; there is no other option. I would be left behind to suffer. (K5)

Theme 3: Enduring loneliness

This theme focuses on the ways through which the participants are coping with their loneliness. Although they are having a lot of difficulties, they have managed and are managing their situation. In this regard, changing attitudes, optimistic thinking, spirituality and positive relationships have played an important role in them being resilient with their situation.

Acceptance of Reality: Narratives from the participants showed a great deal of acceptance with the situation that they were facing. A few of them mentioned that accepting the reality was difficult initially, but later acceptance of it helped them to deal with it with a bit of ease.

Let's accept this, sooner the better. We can't do anything else other than that. (K5)

Futility in Fighting: A few even considered it futile to fight with the situation as they felt they lack any sort of control over it. Contrastingly, some of the participants showed courage and were determined to fight their agony as long as they could.

Whatever I am going through, I will fight it till my last breath, and I will never give up. I will do every possible thing to save us. (K3)

Optimistic Thinking: Some of the participants displayed optimistic thinking related to the diagnosis of the patients. Maintaining optimism with hope for finding a cure helped the caregivers to survive through the difficult phase.

I wanted to stay positive about all this, and I think one thing is still positive- the diagnosis. I know that her detection is at an early stage; there might be some hope, and if we treat it properly, then we can get rid of it as well. (K1)

Understanding Relationship: Strong and close family bonding also enabled coping with the situation. A few mentioned how an understanding relationship among the family members has helped in managing their otherwise depressing situation.

It gave me more courage, and seeing her understanding about this and the support she gave me [teary]... till now she has supported me in everything... I have a strong wife, you know (K1)

Spirituality: Apart from these, spirituality played a significant role in helping the participants to cope with the loneliness they were going through. A few participants relied heavily on destiny and fate in order to get along with their situation.

Whatever is happening is my destiny. Whatever is destined to happen will happen eventually. (K5)

Some of the participants considered their loneliness as punishment from the supreme being.

I surely did something wrong. What! that I am not aware of; otherwise, why I am being punished! Amidst all this I am alone, and there can't be no greater punishment than losing a loved one and being lonely. This is my punishment for my deeds only, nothing else. (K3)

Most participants believed in the notions of an afterlife, greater good and complete reliance on God, which helped them to look beyond their present suffering and gave meaning to their situation.

Everything is God's desire. I am just entrusting my life to my 'lord'. He is the caretaker of the world; He has created this situation; hence he will rescue me. (K3)

By God's mercy everything will turn out okay; I won't agonise about this. and through this my relationship with God has grown. I feel I am closer to Him. (K2)

Discussion

Bury (1982) explored the notions of biographical disruption as a way of understanding the experience of living with chronic illness. This study emphasises that the concept of “biographical disruption” has salience for those caring for family members with cancer and how the tasks of caregiving and induced loneliness can affect the way they see themselves and their sense of self-worth. Loneliness among the family caregivers of cancer patients has received scant attention, and it remains relatively unexplored in existing research on caregiving. Previous studies indicated that there is a decrease in the social network size for most of the patients (Pinquart & Sorensen, 2003). However, the ability to maintain social contact is further constrained among caregivers of individuals with cancer. In addition to this, in order to normalise their disrupted situation, individuals seek to accommodate disruption into their lives by revising their past and future self, where meaning-making is continuous and crucial.

This qualitative study explored how family caregivers experience and perceive loneliness while caring for patients with cancer. Participants’ tasks of caregiving and its demanding nature have induced the feelings of loneliness. The findings of this study are discussed through three themes with a few sub themes and these are- perception and tasks of caregiving, feelings of loneliness, and enduring loneliness.

It is important to acknowledge and develop an in-depth understanding of the problem of loneliness among caregivers of individuals with chronic illnesses such as cancer, from their own perspectives. It is then that suitable interventions can be made to attenuate loneliness among the caregivers. However, there is scarce existing literature that addresses this issue in the Indian context, and the current study was undertaken to fill in that gap through in-depth interviews of caregivers, to explore the facets of loneliness among them. The findings of this study corroborate with those of the existing qualitative research on loneliness among caregivers (Dahlberg, 2007; Stanley, et al., 2010; Tiilikainen & Seppänen, 2016), which underline the complex and multi-faceted nature of the loneliness experience among them. The absence of, or strains in their relationships with others, including close relationships, led to a collapse of their sense of belonging and that caused and accentuated the feeling of loneliness among the caregivers (Baumeister & Leary, 1995). Because caregiving meant complete dedication to the patient’s cause on a consistent and daily basis, it left hardly any time for the caregiver to socialize, and this lack of social inclusion and absence of any meaningful social interaction played a part in creating a sense of loneliness among the caregivers (Brambilla & Leach, 2014). These changes due to the task of caregiving disrupts the taken-for-granted beliefs and assumptions the caregivers hold about their relationships with other people. It is not just the lack of social network that was caused due to the tasking nature of caregiving, but the enormous time

demanding by caregiving work for the patient resulted in the caregivers getting very little time for maintaining their own wellbeing. Caring full time for the cancer patient ensured that the caregivers were left with almost no time for their self-care.

Loneliness is caused by the loss of or/and strain in relationships, especially with their significant “others” (Williams, 2007) and this loneliness can be both emotional and social (Weiss, 1973). Moreover, this loneliness is accentuated by a feeling of self-doubt among the participants since many of them happened to have little knowledge of professional caregiving and this often compelled the participants to rethink their biography and self-conception (Bury, 1982). The absence of help from others and a feeling of being fully responsible for the patient’s caregiving added to their feeling of loneliness. Additionally, one gets a more nuanced understanding of the caregiving process and the associated loneliness when we see it through biographical disruption. The findings show that the biographical disruption largely influenced the affected individuals’ behaviour in the changed conditions. The extent of biographical disruption also had significant bearing on the capacity, or lack thereof, of the affected individual to reconstruct their biography in the new circumstances.

The findings from this study suggest that the feelings of loneliness among caregivers can be attenuated, if not fully prevented, if adequate support can be made available for them during the process of caregiving. For instance, risk of social isolation can be reduced if systemic help can be provided to the caregivers so that they could get some respite from the job at hand, or at the very least, awareness can be raised among them to not just focus on the needs of the patients, but to consciously make an effort at finding time for their self-care, which would then assist them to take care of the patients in a more productive and efficient manner (Ashworth & Baker, 2000).

In addition to raising awareness among caregivers, it is important to raise awareness among the general public regarding the important contributions of the caregivers as well as the extremely difficult nature of their job so that instead of the usual stigma attached to the caregiving work in most orthodox societies, there could be the deserved social recognition and appreciation for the caregivers, which will help reduce the risk of social exclusion and hence, the feeling of loneliness among them.

Conclusion

The contributions made by family caregivers have become extremely significant in the contemporary times since the healthcare related to chronic illnesses is showing a marked shift towards home from hospitals (Daar, et al., 2007). Along with cognitive and psychological interventions, one-on-one and group therapy and resilience training are critically needed to address loneliness as a determinant of health among caregivers. This study emphasises the need

for accessibility to meaningful resources such as social support and palliative care that may enhance well-being among cancer caregivers. It is pertinent to have an informed and in-depth understanding of the various issues and challenges faced by the caregivers to be able to provide them with suitable support system, but in the formal and informal settings of hospitals and homes, respectively. This study has highlighted one of the several issues grappling the caregivers, especially family caregivers, i.e., loneliness and pointed out the underlying need to understand its various facets so that appropriate interventions can be made to enhance the general quality of life of the caregivers, and ensure their physical and mental wellbeing.

Notes

- 1 Cancer patient's significant others are often referred as their caregivers. Caregivers play multiple roles in supporting the cancer patients, in terms of facilitating their treatment and overall wellbeing.

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