

Stigma and Family reaction among Caregivers of Persons Living with Cancer

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Abstract: *Cancer stigma refers to a negative or undesirable perception of a person affected by cancer. Stigma can be internal—it can affect self-perception of survivors, causing guilt, blame or shame. It can also be enacted, causing discrimination, loss of employment or income, or social isolation. It can come from misinformation, lack of awareness and deeply-engrained myth. The present study consisted of 300 caregivers of persons with cancer was selected based on simple random sampling, and with inclusion and exclusion criteria. Those patients satisfying the inclusion and exclusion criteria and attending both outpatient and inpatient services of cancer specialty hospital in KIDWAI Bangalore, Karnataka were selected randomly. The data was collected from the patients & caregivers of persons living with cancer who fulfill the inclusion/exclusion criteria were taken up for the study after their consent. Semi structured interview schedule were used to understand the stigma and family reaction. The interviews and the instruments were administered by research experts.*

Key Words: *Stigma, Family reaction, Caregivers, cancer*

I. Introduction

Cancer can affect the patients' and caregivers' family and social well-being, especially in areas related to talking about the illness, sexual well-being, changing family roles and responsibilities, and maintaining individuals' social support systems (Badr&Manne, 2009). Problems occur when patients and caregivers hide worries from one another, and avoid talking about sensitive issues associated with cancer and its treatments. Family caregivers experience role overload when they take on patients' household or family responsibilities, in addition to their own (Kuijer&Vess, 1985). Difficulty communicating and negotiating family roles can hinder patients' and caregivers' ability to support one another, can decrease couples' intimacy, and have a detrimental effect on marital and family relationships (Manne&Porter, 2005).

Cancer is a class of diseases in which a cell, or a group of cells display uncontrolled growth, invasion and sometimes metastasis. These three malignant properties of cancer differentiate them from being tumors, which are self-limited and do not invade or metastasize. Most cancers form a tumor but some like leukemia do not. The branch of medicine concerned with study diagnosis, treatment and prevention of cancer is oncology. Cancer can affect people of all ages with the risk for most types increasing with age cancers are primarily an environmental disease due to lifestyle and environmental factors and due to genetics. Caregivers usually define the onset of caregiving as the time of patients first cancer diagnosis; ideally intertuous for the care giver should began then. The interventions for the caregiver includes Education and information, Counseling and psychotherapy, Home care services for the cancer patient, Hospice care for the cancer patient, The family meeting, Psychoeducation

Modern hospital care has led to increase in home based palliative care services, with informal caregivers assuming responsibility for the majority of care. In response, health policy emphasizes the provision of palliative care services in which both patient and care receive adequate support throughout illness and death. While the emotional needs of cares have been extensively researched, their practical needs with respect to the provision of physical care are yet to receive systematic attentions. Home based palliative care services have been insufficiently focused on assisting informal caregivers adequate-practical nursing skills. Professional advice represents a potentially effective method of increasing carers confidence and their ability to undertake practical aspects home-based care. Evidence suggests that nurses and other health providers may better assist home based carers by providing the information and skills training necessary to facilitate this. This may necessitate the involvement of carers in the design and testing of new educational interventions. In India there is a vast amount of cancer patients, they suffer due to stigma. So there is need for educating their caregivers about the vast promising developments in the cancer treatments and this can bring up their pleasure again. Families often

dismiss the first indication that a family member maybe mentally unstable, facing the situation as stressful and painful. It is noted that difficulty accepting a chronic, severe illness is normal, whereas acceptance of relative with cancer is especially difficult due to stigma attached with this. Caring for a loved one with cancer is no easy task. Physical and emotional care can be time-consuming and exhausting. Not only does it require caring for someone you love at home, but it also means facing your own concerns about the diagnosis and eventual outcome of the disease. Practical concerns, such as worries about financial issues and time management, are also common. This can be especially true because of the stigma attached to a cancer diagnosis. The idea of cancer cells growing in one's body may conjure thoughts of being attacked by an unknown force that cannot be controlled. It can be difficult to learn about a disease when you do not know where to start.

II. Scope and Objective

Hence the present study will help us in formulating family intervention improve their stigma and family reaction of caregivers of persons with cancer. The purpose of the present study was to examine stigma and family reaction of caregivers of persons with cancer.

Objectives:

- To find out the stigma among caregivers of persons with cancer
- To find out the family reaction among caregivers of persons with cancer

III. Research Methodology

The present study has adopted a descriptive research design to describe the variables associated with various psychosocial aspects of caregivers of persons with cancer. It aims at describing the variables associated with the psychosocial correlates and problems of cancer patients with caregivers due to cancer and its treatments. The variables ranged from socio-demographic details and quality of life. The caregivers of patients diagnosed with cancer (acute, middle or end of life phase of cancer) who are admitted in cancer specialty hospital in KIDWAI (Kidwai Memorial Institute of Oncology) Bangalore. A sample of 300 caregivers of persons with cancer was selected based on simple random sampling, and with inclusion and exclusion criteria. Those patients satisfying the inclusion and exclusion criteria and attending both outpatient and inpatient services of cancer specialty hospital in KIDWAI Bangalore, Karnataka were selected randomly. Based on the pilot information regarding number of inpatient and outpatient at the KIDWAI centers in Bangalore random numbers was taken care of the patient load at the given center. The data was collected from the patients & caregivers of persons living with cancer who fulfill the inclusion/exclusion criteria were taken up for the study after their consent. Hospital registration number during the study period was used to obtain a representative random sample. Semi structured interview schedule were used to understand family reaction and stigma. The interviews and the instruments were administered by research experts.

IV. Result

Table: 1 Stigma of caregivers of person living with cancer

Variables	Frequency	Percentage	Variables	Frequency	Percentage
Stigma-1			Stigma-5		
Not at all	259	86.3%	Not at all	201	67.0%
A little	16	5.3%	A little	38	12.7%
Some	21	7.0%	Some	49	16.3%
A lot	4	1.3%	A lot	12	4.0%
Stigma-2			Stigma-6		
Not at all	293	97.7%	Not at all	221	73.7%
A little	3	1.0%	A little	29	9.7%
Some	1	0.3%	Some	39	13.0%
A lot	3	1.0%	A lot	11	3.7%
Stigma-3					
Not at all	221	73.7%			
A little	16	5.3%			
Some	40	13.3%			
A lot	23	7.7%			
Stigma-4					
Not at all	223	74.3%			
A little	21	7.0%			
Some	47	15.7%			
A lot	9	3.0%			

The distribution of stigma-1 represents the caregivers expression about how they would be treated by their neighbors. The majority of them reported that they would not be treated any differently by their neighbors

86.3% (N=259), this is followed by some change 7 % (N=21), a little difference 5.3% (N=16), and a lot of change in their neighbors treating them 1.3% (N=4), respectively.

The distribution of stigma-2 caregivers opinion about whether others will reluctant to marry into their family. The majority of them 73.7% told not at all, 3% of told that other will reluctant to marry into their family followed by a little 1% and 1% a lot and some.

The distribution of stigma-3 describes whether caregivers were reluctant to reveal their secret to others. The majority of them said not at all 73.7% (N=221), this was followed by some 13.3% (N=40), 7.7% (N=23), a lot and 5.3 % (N=16), a little.

The distribution of stigma-4 reveals that due to the patient’s illness, their relatives/friend are stopped visiting their family. The majority of them said not at all stopped visiting their family 74.3 % (N=223), 15.7% (N=47), of them said by some time stopped visiting their family. 7 % (N=21), of them said with a little stopped visiting their family and 3 % (N=9), of them said with a little stopped visiting their family.

The distribution of stigma-5 reveals at what level the patient families hesitate to visit the hospital. It can be seen from the above table the majority of them said that not at all patient families hesitate to visit hospitals, 67% (N=201), while 16.3% (N=49) said that some of patient families hesitate to visit hospitals, 12.7%(N=38) said that a little patient family hesitate to visit hospitals, 4%(N=12) said that a lot patient families hesitate to visit the hospital.

The distribution of stigma-6 describes the patient families comfortable with their own relatives and friends. The majority of the respondents said that not at all comfortable with their own relatives and friends 73.7% (N=221), while 13% (N=39), have told that some of them comfortable with their own relatives and friends, 9.7% (N=29), said that a few of them comfortable with their own relatives and friends and 3.7%(N=11), said that a lot more comfortable with their own relatives and friends.

Table: 2 Semi structured Interview Schedule of caregivers of person living with cancer

Variables	Frequency	Percentage
Family’s reaction		
Denial	51	17.0%
Shock	214	71.3%
Fearful	153	51.0%
Angry	10	3.3%
Depressed	55	18.3%
Acceptance	15	5.0%
Surgery reaction		
Denial	30	10.0%
Shock	117	39.0%
Fearful	192	64.0%
Angry	16	5.3%
Depressed	110	36.7%
Acceptance	25	8.3%
Cancer Surgery reaction		
Karma	44	14.7%
Better care of patient	218	72.7%
Bad time	108	36.0%

The above table describes the care giver’s reactions about the patient's condition. The result shows that the majority 71. 3% (N=214) of the caregivers had a shock as a reaction while 51% (N=153) reacted with fear, 18.3% (N=55) were having a depressed reaction, 17% (N=51) were in denial, 5% (N=15), were accepted, and 3.3% (N=10), were angry. And then describes the care givers’ reaction about patient’s hospitalization. The majority of the caregivers had fearful reaction 64% (N=192), while 39% (N=117), had shock as reaction, 36.7 % (N=110), were having a depressed reaction, 10% (N=30), had denial 8.3% (N=25), had acceptance and 5.3% (N=16), had anger as reaction. And the distribution care giver’s opinion about patient’s surgery and condition. The majority of the caregivers opinion was Better care of patient 72.7% (N = 218), 36% (N = 108), of them felt it was bad time and 14.7% (N = 44), of them felt that it was due to karma.

V. Discussion

Stigma among caregivers of patients with cancer

The present study reported that majority of them reported that they would not be treated any differently by their neighbors 86.3% (N=259), this is followed by some change 7 % (N=21), a little difference 5.3% (N=16), and a lot of change in their neighbors treating them 1.3% (N=4), respectively. The majority of them 73.7% told not at all, 3% of told that other will reluctant to marry into their family followed by a little 1% and 1% a lot and some. The majority of them said not at all 73.7% (N=221), this was followed by some 13.3% (N=40), 7.7% (N=23), a lot and 5.3 % (N=16), a little. The majority of them said not at all stopped visiting their family 74.3 % (N=223), 15.7% (N=47), of them said by some time stopped visiting their family. 7 % (N=21), of them said with

a little stopped visiting their family and 3 % (N=9), of them said with a little stopped visiting their family. The distribution of stigma-5 reveals at what level the patient families hesitate to visit the hospital. It can be seen from the above table the majority of them said that not at all patient families hesitate to visit hospitals, 67% (N=201), while 16.3% (N=49) said that some of patient families hesitate to visit hospitals, 12.7% (N=38) said that a little patient family hesitate to visit hospitals, 4% (N=12) said that a lot patient families hesitate to visit the hospital. It also reports that majority of the respondents said that not at all comfortable with their own relatives and friends 73.7% (N=221), while 13% (N=39), have told that some of them comfortable with their own relatives and friends, 9.7% (N=29), said that a few of them comfortable with their own relatives and friends and 3.7% (N=11), said that a lot more comfortable with their own relatives and friends. This result can be matched with previous study results Interactions with caregivers there has been a shift in care for cancer patients in recent years. Improvements in medicine and technology have resulted in individuals with cancer living longer, even with advanced-stage disease (Hazelwood et al., 2012). Coupled with the transfer in clinical care from inpatient to outpatient settings, these movements have brought the cancer caregiver to the forefront of the care team (Van Ryn et al., 2011). Caregivers for cancer patients experience psychological, social, spiritual, and physical burden as a result of their role (Skalla et al., 2013). They report elevated rates of anxiety, depression, and guilt, as well as temporal and financial strain (Applebaum et al., 2013). Having to assume additional responsibilities such as domestic tasks and the patients' activities of daily living often prevent caregivers from engaging in their own self-care leading to cardiovascular disease (Schneiderman et al., 2012), insomnia (Skalla et al., 2013), and even premature death (Christakis and Allison, 2006). Caregiver burden can also have an effect on cancer patients and their internalization of stigma. More stigmatized types of cancer are linked to poorer quality of care; for example, caregivers of lung cancer patients who were smokers report being more likely to blame them for their current situation (Lobchuk et al., 2008 as cited in ElseQuest and Jackson, 2014).

Family reaction among caregivers of patients with cancer

Regarding the care giver's reactions about the patient's condition, the result shows that the majority 71.3% (N=214) of the caregivers had a shock as a reaction while 51% (N=153) reacted with fear, 18.3% (N=55) were having a depressed reaction, 17% (N=51) were in denial, 5% (N=15), were accepted, and 3.3% (N=10), were angry. And then describes the care givers' reaction about patient's hospitalization. The majority of the caregivers had fearful reaction 64% (N=192), while 39% (N=117), had shock as reaction, 36.7% (N=110), were having a depressed reaction, 10% (N=30), had denial 8.3% (N=25), had acceptance and 5.3% (N=16), had anger as reaction. And the distribution care giver's opinion about patient's surgery and condition. The majority of the caregivers opinion was Better care of patient 72.7% (N = 218), 36% (N = 108), of them felt it was bad time and 14.7% (N = 44), of them felt that it was due to karma.

VI. Conclusion

This study concluded that there stigma found in caregivers cancer patients. Family caregivers of cancer patients receive little preparation, information, or support to carry out their care giving role. However, their psychosocial needs must be addressed so they can maintain their own health and provide the best possible care to the patient. We need to address the issue of stigma and silence associated with cancer by empowering cancer survivors and their families to share their cancer experiences with their communities and to conduct anti-stigma campaigns to illustrate that cancer is not necessarily a "death sentence;" that it can be survivable with early detection and proper treatment; and that cancer survivors can lead healthy life.

Skills-building techniques for families to identify and respond positively to psychological distress in their patients feel comfortable enough to speak about their illness instead of skirting the topic. Sensitizing the public about the impact of stigma on patients can reduce the fear-inducing experiences of chronic illnesses.

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References

- [1]. Applebaum AJ, Farran CJ, Marziliano AM, et al. (2014) Preliminary study of themes of meaning and psychosocial service use among informal cancer caregivers. *Palliative & Supportive Care* 12: 139–148
- [2]. Badr H, Taylor C. (2009). Sexual dysfunction and spousal communication in couples coping with prostate cancer. *Journal of Psychooncology*. 18:735–746.
- [3]. Christakis NA and Allison PD (2006) Mortality after the hospitalization of a spouse. *New England Journal of Medicine* 354: 719–730
- [4]. Else-Quest NM and Jackson TL (2014) Cancer stigma. In: Corrigan P (ed.) *The Stigma of Disease and Disability*. Washington, DC: American Psychological Association, pp. 165–182.
- [5]. Hazelwood DM, Koeck S, Wallner M, et al. (2012) Patients with cancer and family caregivers: Management of symptoms caused by cancer or cancer therapy at home. *Heilberufe Science* 3: 149–158

- [6]. Kuijter RG, Buunk BP, Ybema JF, Wobbes T. (2002). The relation between perceived inequity, marital satisfaction and emotions among couples facing cancer. *British Journal of Social Psychology*. 41:39–56.
- [7]. Lobchuk MN, McClement SE, McPherson C, et al. (2008) Does blaming the patient with lung cancer affect the helping behavior of primary caregivers. *Oncology Nursing Forum* 35: 681–689
- [8]. Manne SL, Norton TR, Ostroff JS, Winkel G, Fox K, Grana G. (2007). Protective buffering and psychological distress among couples coping with breast cancer: the moderating role of relationship satisfaction. *Journal of Family Psychology*. 21:380–388.
- [9]. Manne SL, Ostroff JS, Norton TR, et al. (2006). Cancer-related relationship communication in couples coping with early stage breast cancer. *Psychooncology*.15:234–247.
- [10]. Porter LR, Keefe FJ, Hurwitz H, Faber M. (2005). Disclosure between patients with gastrointestinal cancer and their spouses. *Journal of Psycho oncology*. 14:1030–1042.
- [11]. Schneiderman N, Kim Y and Shaffer KM (2012) Spouses of patients with cancer have an increased risk of cardiovascular disease: What do we know about this link? *Circulation* 125: 1721–1722.
- [12]. Skalla KA, Smith EM, Li Z, et al. (2013) Multidimensional needs of caregivers for patients with cancer. *Clinical Journal of Oncology Nursing* 17: 500–506.
- [13]. Van Ryn M, Sanders S, Kahn K, et al. (2011) Objective burden, resources, and other stressors among informal cancer caregivers: A hidden quality issue? *Psycho-oncology* 20: 44–52.
- [14]. Vess JD, Moreland JR, Schwebel AI. (1985). A follow-up study of role functioning and the psychological environment of families of cancer patients. *Journal of Psychosocial Oncology*. 3(2):1–13.