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A burden shared: the financial, psychological, and health-related consequences borne by family members and caregivers of people with cancer in India

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Abstract

In India, about 1.4 million new cases of cancer are recorded annually, with 26.7 million people living with cancer in 2021. Providing care for family members with cancer impacts caregivers' health and financial resources. Effects on caregivers' health and financial resources, understood as family and caregiver "financial toxicity" of cancer, are important to explore in the Indian context, where family members often serve as caregivers, in light of cultural attitudes towards family. This is reinforced by other structural issue such as grave disparities in socioeconomic status, barriers in access to care, and limited access to support care services for many patients. Impacts on family caregivers' financial resources are

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particularly prevalent in India given the increased dependency on out-of-pocket financing for healthcare, disparate access to insurance, and limitations in public expenditure on healthcare.

In this paper, we explore family and caregiver financial toxicity of cancer in the Indian context, highlighting the multiple psychosocial aspects through which these factors may play out. We suggest steps forward, including future directions in (1) health services research, (2) community-level interventions, and (3) policy changes. We underscore that multidisciplinary and multi-sectoral efforts are needed to study and address family and caregiver financial toxicity in India.

Keywords

Financial toxicity; Cancer equity; Global oncology; India; South Asia; Family financial toxicity

Manuscript

In India, about 1.4 million new cases of cancer are recorded annually, with 26.7 million people living with cancer in 2021. Such an estimate is likely an under-representation of the true number given the possibility of under-recording (1). Approximately 1 in 9 individuals in India will develop cancer in their lifetime. In India as in many places in the world, family plays a critical role in caring for the patient, reflecting cultural attitudes towards family, barriers in access to care, and costs associated with professionally provided supportive care services. While western societies are often described as “individualistic”, Indian society commonly embraces collectivism, which relies on interdependence, with family taking the center stage (2). This is the case despite the drift towards nuclear families from joint families, especially in urbanized parts of India (3). Indian families therefore often play a critical role in caregiving. This collectivist nature can also be due to deep rooted religious practices in India. Acknowledging the vast heterogeneity of cultures and identities within India, 80% of India is religiously and culturally Hindu, the strong sense of

familial duty may link to concepts in Hinduism such as *dharma* and *karma* (4). Dharma is defined as a component to achieve moksha, while karma refers to the moral effects generated by an individual's actions that can impact future lives (5). The particular case of individuals caring for the elderly parents is known as "*seva*," and it showcases the collectivist nature of Indian culture where individual sacrifices help promote social harmony (6). It is in the context of this cultural milieu that the financial and psychological costs of cancer care in India impact not only patients but their family members and caregivers.

The difficulty in accessing cancer care facilities is pertinent in India. Patients travel long distances for accessing cancer care facilities (7). Given the role of family in caring for patients with cancer, and the often resource-limited setting in which care is provided, the impact of caregiving on families in India is a key area of study and intervention. In this commentary, we explore the evidence, potential interventions, and future directions addressing how the financial toxicity of a cancer diagnosis can affect family members, drive detrimental effects of their own access to care, and have negative implications for their mental and emotional wellbeing. We note that shedding light on the Indian context may have lessons for other similarly resourced settings, and underscore the importance of multinational collaboration in research, intervention design, and policy.(8–11)

1. Financial toxicity

Financial toxicity describes patient-facing problems related to the costs of treatment (12); the larger context includes direct or indirect effects on the physical and financial health of patients, their families, and society (13). Although financial toxicity is best studied in the USA, work from lower-middle-income countries (LMICs) like India suggest distinct and complex facets of financial toxicity, especially in the context of high rates of poverty (11,14). Paralleling the

experience in other countries, in India, families of patients often serve as primary caregivers. Families of patients can therefore bear high out of pocket costs and reduced working hours due to the cancer diagnosis of their relatives. On average, caregivers often halve their working days to fulfill their duties in caring for their family, with implications for their ability to earn (15). Other than the decreasing working hours, caregivers are less likely to be employed, are in lower-paid jobs, work from home, or need to take leave without pay, further decreasing their income (16). Beyond the loss of income, other sources of additional financial strain include out-of-pocket expenditure, and travel and accommodation costs (17).

The problem of financial toxicity is salient in India, where there is low governmental investment in public healthcare, poor insurance coverage, and high expenditure relative to household income. In 2021, public healthcare made up less than 2% of India's gross domestic product (18). A study in 2014 demonstrated that up to 86% of the rural population and 82% of the urban population in India do not have any form of medical insurance (19). The lack of medical insurance in the majority of the Indian population and the delay in insurance payouts for those who do have insurance results in reliance upon out-of-pocket (OOP) expenditures as the primary source of funding healthcare in India (20). The World Health Organization (WHO) reported a drastic difference in the proportion of total healthcare expenditures taken up by OOP expenditures between India and the world average. While 67.78% of total healthcare expenditures in India is from OOP expenditures, the global average is at 18.2% (21).

Therefore out-of-pocket expenditures for healthcare in India directly impacts patients' families. Financing cancer care often involve distress financing, when an individual is forced to sell property, pawn jewelry, or use a significant portion of their savings. Approximately 60% of rural and 40% of urban healthcare procedures in India are financed by distressed financing (22,23).

Distressed spending is likely to drive families into poverty; 55 million Indians were reported to be driven into poverty due to healthcare-related out-of-pocket expenditures in 2017 alone [18].

It is important to note that within India, there are vast differences in the experience of financial toxicity by family caregivers. Recent work has elucidated factors associated with increased risk of financial toxicity including low household income, female gender, use of private healthcare facilities which are likely to be more expensive, and accumulation of debt over time (14). Of particular note is the differential impact of financial toxicity between male and female caregivers (24,25). While male caregivers can face limitations in their working hours and can face a decrease in income, given that female caregivers are more likely to serve as the "primary caregivers," they face greater restrictions in their working hours and stand to face a greater impact in their income (26). Given these differences in the experience of financial toxicity, efforts to decrease financial toxicity borne by patients and families should be designed with a lens of equity and should target those most at risk.

2. Mental and physical health

Family members who serve as caregivers for loved ones with cancer have detrimental impacts on their mental and physical health. Cancer caregivers have an increased likelihood of experiencing depression, social isolation, insomnia, and financial and work stress (27). A review done in patients with head and neck cancer (HNC) and their families showed that 9 to 57% of caregivers suffered from depression and anxiety (28). Another study found that anxiety disorders and depression are 1.7 times and 1.5 times, respectively, more common in caregivers compared to non-caregivers (29). Factors that influence the risk of mental health conditions in HNC caregivers were also reported by some studies. These factors include female gender, lower educational level, and lack of social support provision.

Perceived stigma is another cause of mental health distress in family caregivers in India (30). Patients report stigma in the form of social isolation, harassment, and loss of employment opportunities. Stigma that cancer patients in India face can include the belief that their diagnosis is a repercussion of their own actions in this lifetime or that of a previous one, which is based on the idea of and belief in *karma*, held by many in India. The commonly held thought that cancer is a contagious condition exacerbates the problem of stigma [24]. Agoraphobia, an anxiety disorder involving excessive fear of some social situations, is reported in caregivers [22], and it is possible that there is a link between perceived stigma and agoraphobia.

The detriment to the mental health of family caregivers in India is exacerbated by the gap in individuals who need help and those who are able to receive good-quality help for their mental health problems. It is estimated that only 10% of individuals with mental health problems receive proper interventions in India (31). Both poor mental health service provision and utilization are causative factors for this gap (32). In a report by NHMS, the number of psychiatrists in India remain low, from 0.05 per 100,000 people in Madhya Pradesh to 1.2 per 100,000 in Kerala (33). The mental health service provided is also often poor in terms of quality (34). Stigma is believed to increase hesitancy in seeking help, which hinders diagnosis and treatment (35).

Primary caregivers of patients with cancer also often face negative impacts on their physical health. Caregiving can cause physiological and physical strain that can result in an impairment of caregivers' physical health. Goswami et al. presented interviews with primary caregivers of oral cancer patients in India where they acknowledged that taking care of their relatives, while tending to other matters, such as chores, causes them to lose out on self-care or taking care of their basic needs (36). Another study performed in Ghana reported that family caregivers may face body aches, loss of appetite, fatigue, and sleep deprivation (37).

Physical health and mental health problems due to caregiving can be interrelated. Psychological distress is proposed to be another causative factor of physical health impairment in caregivers (38). Psychological distress, such as depression, can result in changes in hormone levels, an increased susceptibility to infections, and a disruption of self-care routine. Caregivers with depression have been shown to overreport physical health problems (39–41). In addition, increasing physical health problems can in turn cause a higher risk of mental health problems [32].

A study in Pune, India, explored the physical and mental impacts of caregiving on family members. The study showed a significant proportion of respondents felt uncertain about the patient's future, and physical health impacts such as fatigue and lack of sleep, a small proportion, reported feeling extremely entrapped (42). This could also be potentially associated with the entrenched notion of duty towards family that many do not prefer terming it a "chore". Importantly, the results of this study also suggest that caregiver stress can negatively impact the quality of care a patient receives.

It is also noteworthy that there the experience of mental and physical strain by family caregivers differs based on multiple factors, such as gender. Many published studies on caregiver burden across a wide range of conditions, including cancer, have demonstrated that the majority of caregiver burden falls disproportionately on women. For instance, a study on caregiver burden among family caregivers for patients with psychiatric conditions estimates that women are twice more likely to serve as caregivers, while 55% of family caregivers for cancer patients were female (24,43). Even where there is no significant difference in the amount of time spent caregiving for family members between male and female caregivers, female caregivers are shown to experience greater mental and physical health strain compared to male

caregivers (44–47). This difference could be attributed to (1) differences in the stressors in their roles as caregivers and/or (2) differences in the experience of burden and coping strategies (48). It can be argued the men and women experience different privileges, opportunities, and responsibilities in society which leads to a disparity in the nature and intensity of stressors in their roles as caregivers. Women in India are more likely to forego other aspects of their life (such as work, and self-care) for the sake of caregiving. Secondly, prior work suggests that the emotional coping responses may vary on average between women and men, necessitating efforts that cater specifically to those most likely to perform the role of caregiver (49). This disproportionate experience of caregiver burden in the form of poorer mental and physical health could be amplified in LMICs such as India.

3. Steps forward

Overall, family members who serve as informal primary caregivers for their relatives with cancer are especially common in countries like India due to reasons such as cultural and societal pressure. As family members take on roles as caregivers, they face other problems such as financial stress, poorer mental, and physical health.

There is a dearth of literature on the impact of caregiving on family caregivers in India, led by experts in India. Further exploration is required to develop scoring metrics to guide actionable efforts by clinicians and direct policy-based initiatives. For instance, caregivers' mental and physical health problems can be addressed by encouraging clinicians to identify and refer high-risk family caregivers to welfare organizations, based on developed scoring metrics (50). Other possible interventions include the implementation of psychological interventions, such as cognitive reframing, which have shown to be effective in the past (51).

Firstly, local research that promotes understanding of family financial toxicity and health impacts on family caregivers is needed. One recent study translated and validated the COST-FACIT metric for financial toxicity into Hindi and Marathi; item 12 in the COST-FACIT metric explores family financial toxicity, asking whether a patient's "illness has been a financial hardship to my family and me." (52). However, more context-specific work that examines metrics and interventions are is needed. Indeed, many studies evaluating the effectiveness of interventions are based in high-resource settings and may not be directly applicable in LMICs such as India (53). Research must actively involve individuals who are familiar with the situation and the resources in the local setting in order to eventually develop sustainable interventions. These individuals include patients and patient advocates, research scientists, health economists, health policy experts, and community leaders (54). Research should also involve both quantitative and qualitative study designs. While quantitative methods aid in producing estimates for health impacts and evaluating interventions (55), qualitative methods allow exploration of human behavior that cannot be adequately expressed quantitatively (56).

With the importance of interventions at the clinic to identify caregivers at high risk of financial toxicity or detrimental health impacts, screening metrics have to be developed. These screening metrics have to be contextualized to India due to the strong role of family in caring for family members. Numerous tests to measure caregiver burden, financial toxicity, and quality of life have been developed and assessed over the years [43,44]. However, it will be important to compare the various existing tools to determine an optimum one or develop a novel tool to best identify family caregivers in India at high risk of (1) financial toxicity or (2) poor mental and physical health. These tools should then be actively employed in the clinic. For instance, families identified to suffer from financial toxicity should be directed to receive financial assistance and guidance from financial navigators. Financial navigators conduct a comprehensive evaluation of the patients' risk for financial toxicity and refer them to suitable

resources in empowering patients to tend to their healthcare needs. Case studies have shown examples of how financial navigators could streamline care for patients (59). Financial navigators can be considered under the larger group of patient navigators, who are a multidisciplinary group of professionals who can facilitate patients' access to healthcare, including cost considerations (60).

Lastly, policies to support family caregivers in India should also be bolstered and introduced. For example, the government of India has introduced the Ayushman Bharat Pradhan Mantri Jan Arogya Yojana (AB-PMJAY) program. Introduced in 2018, AB-PMJAY provides up to Rs 500,000 per family per year for patients with cancer, covering the poorest 40% of India's population [45]. However, to address the financial and cost-related health effects borne by family members, such programs should also address indirect costs of care such as transportation, housing during treatment, and missed work especially for daily wage earners. To manage the costs of cancer treatment, better insurance policies and efforts to increase insurance provision and utilization by people should be established. Initiatives offering professional help to take care of cancer patients at affordable prices can alleviate the health of family caregivers [46].

4. Conclusion

Overall, informal caregiving by family members is common in LMICs such as India. Caregiving is shown to have impacts on family caregivers' health and financial resources. These impacts are only exacerbated in India where personal funds form the bulk of healthcare expenditure, and where there are insufficient existing measures to adequately support family caregivers. Future work in research, patient-level and community initiatives, and nation-wide or region-wide policies is necessary to support patients with cancer and their families and caregivers.

Author contributions

SR and ECD wrote the first draft of the manuscript. VT, FC, TP, BJ, and AM edited and reviewed the manuscript. All authors reviewed and accepted the final version of the manuscript.

Declarations

Ethical approval

Not applicable

Competing interests

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~~Authors' Contributions~~

~~SR and ECD wrote the first draft of the manuscript. VT, FC, TP, BJ, and AM edited and reviewed the manuscript. All authors reviewed and accepted the final version of the manuscript.~~

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