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# An Interpretative Phenomenological Analysis (Ipa)
# Study On The Motivations And Needs Of Cancer Caregivers
# Among Indian Families

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## Abstract

Background: Caregiving, a matter of utmost concern, although has always been a hidden cause. Caregiving is often taken as a role of duty which was always meant to be, especially in the Indian context. While the impact of family caregiving has been proved in numerous other similar studies, many of such works have focussed on probing the external factors similar to socio-economic status, availability to knowledge and resourceful assets, and social-support as the primary determinant of caregiver welfare progress. This study explores the motive and inspiration behind the act of family caregivers providing social support, strength and incentive force. It also critically examines how internal appraisal procedures of such incentives can be both appreciated and valued as well as negatively judged.

Methods: This study employed an interpretative phenomenological analysis (IPA) to study the motivating force and inspirations and the basic internal appraisal processes of Indian family caregivers who were looking after a female cancer patient in the household scenario. The first participant's interview transcript was repeatedly read, followed by initial coding in a line-by-line fashion to capture aspects of significance, as well as offer possible interpretations of underpinning meaning and judgements. These initial codes were then qualitatively integrated to develop tentative conditional themes before the next candidate's transcripts were formerly started and focussed upon. Once all interviews were collectively examined, the initial codes and themes from the other cases were explored, compared, investigating the density of differences and similarities in the statements of all three participants (N = 3). The sample consisted of participants aged 21 and above who were identified to be the primary caregivers of cancer patients. Data collection was conducted with the family caregivers.

Results: Findings revealed six themes that could either nurture or diminish caregiver wellbeing: 1) Recognition and appreciation of allegiance and loyalty (caregivers were inspired to follow their support duties and presumed roles in order to avoid remorse later), 2) Weakening and reducing the pain, hurt and agony (caregivers were motivated to relieve their family member’s ache and hardships), 3) Experiencing the bonding and closeness (caregivers were highly motivated to spend quality time together with their loved ones), 4) Maintaining appreciation, regard, respect and acknowledgement (caregivers were motivated to express their gratefulness to their family member by caregiving), 5) Negotiating and traversing the shift and substitution (caregivers were motivated to acclimatize consequently to changes in the illness prognosis) and 6) Adjusting to impermanency and temporality (caregivers were motivated to respond consequently to their family member’s illness trajectory).

Conclusion: Attaining and strengthening one’s sense of autonomy and self-reliance appears to be the focus of caregiver’s motivating force with positive meanings and consequently nurturing one’s welfare outcomes in the caregiving trajectory. These findings are in accordance and further work and recommendations for healthcare professionals working with family caregivers of palliative care cases.

Keywords: Cancer, Caregiver, Patient Care, Motivation, Qualitative Research

## Introduction

The experience of cancer family caregiver can be likened to an in-congruency. What could elicit a sense of pleasure, acknowledgement and gratefulness and appreciation, could also bring about deteriorating feelings of anxiety, distress, torture and pain. While some have related the caregiving trajectory to the metaphor of mountain thrusting (Zhou et. Al, 2018), the exploration of a family caregiver generally spans beyond a simple time lapse of days or weeks. In this expansive journey, they sail and negotiate through the emotions and feelings of fear, impermanence, or lifelong penalty. The role of the family caregiver is often heterogeneous, complicated and everlasting.

Regular duties involve managing medical administrations, negotiating the healthcare system, and taking charge of other dependents, alongside furnishing physical, internal and emotional support throughout the illness journey (Fletcher et. al, 2012; Williams et. al, 2014). Numerous cases of caregivers are often infrequently equipped with formal, sufficient or reasonable training, nor do they retain adequate skill set, awareness and forthcoming nature before they find themselves caring for a loved one under their duty and responsibility of caregiving.

Family caregivers are also exposed to direct, control, govern and command the vast magnitude of emotions and feelings as they come to terms with the changes and occasional losses, in their individual lives (Northouse et. al, 2012). These complicated circumstances are not limited to a small majority as well. Despite strong global advancements in medical technology and healthcare systems, aged population still remain largely susceptible to fatal, incurable and terminal morbidities that are debilitating (Bähler et al, 2015). In the United States alone, over 40 million caregivers tend to their ailing family members annually (Verbakel etal., 2014), while an estimated 80% of cases in Europe procuring long-term care are attended to by informal caregivers. With the anticipated number of elderly in the world soaring to 2 billion by 2050 (WHO, 2018), there will clearly be a need of caregiving training in healthcare settings. The impact of family caregiving stressors has been well-researched (Borsje et al., 2016; Pinquart et al., 2003; Schulz & Sherwood, 2018; Vaingankar et al., 2016) with an active exploration of caregiver wellbeing, burnout and its effect on the society at large. Accompanying the present literature, it has been stated that the traits of resilience, adaptability and transformational growth have been displayed by the family caregivers in situation of adversity. The common thread that impacts both caregiver debilitation and weariness as well as resilience appears to be a lack of sufficient awareness and adaptability as well as training. This process requires the individual to constantly change endeavours in ideas, opinions, notions, beliefs and actions in order to manage internal or external demands that are considered stressful.

Despite this evidence that one's psychological and cerebral resources are center to maintaining one's welfare and health, time and again, many studies consider external factors such as socio-economic status, availability and accessibility to resources and availability of social support as the primary causation for the degree of caregiver wellbeing. Thus, these studies often recommend pragmatic interventions that concentrate on enhancing external circumstances accordingly and consequently.

## Caregivers: The Silent Hidden Victims

A cardinal feature of the cancer journey revolves around the fact that it affects both the patient and the family who may also feel sick, helpless, anxious, frustrated and fearful. Once the treatment starts, the daily routines of each family member tends to modify or change (National Cancer Institute, 2018).

Other related issues that might come up with are (National Cancer Institute, 2018).:

a) **Changing life roles**: The patient family is faced with sudden changes and all members are usually bound to take up new roles, responsibilities and might have their own challenges and decisions depending upon the type of family and home environment. For example, the spouse may have to perform more duties than normal, children might perform household chores from a young age, and a parent might have to leave his/her job in order to stay with the child. This might be a difficult scenario to accept and accommodate to.

b) **Money**: Cancer treatments are usually expensive and can cause financial burden to the family. It can use up all the savings of the family or halt the expenditure. It may also strain the working family member, if there is only one earning member in the family, and also put burden on the family to abridge with the matters of insurance and other money related issues.

c) **Living arrangements**: In some cases, people might have to change where they live or whom they live with. This situation can be supremely exhaustive and stressful for the family and the patient and might make them feel dependent.

d) **Daily activities**: The patient and the family might require extra assistance with daily chores and taking care of the house. In some cases an extra helper for the domestic chores is also observed for better assistance.

## Indian Caregiving

According to National Alliance for Caregiving (2015), the process of Informal Caregiving is defined as the art of providing personal and medical assistance by a person who is unpaid, who performs all the household tasks, and gives special attention for arranging outside services and regular hospital visits. The psychosocial wellbeing of the caregiver evidently affects the general evaluation of the quality of care received by the patients. For example, the results of a survey study done by Litzelman et al. (2016) on 689 patients and their caregivers, showed how ratings of lower quality of care reported by the patients was influenced by high levels of depression among the caregivers. Therefore, it is completely essential for the clinicians to gather and evaluate patient and caregiver needs independent of each other as the key challenges and difficulties faced by both are similar yet quite different and exhaustive.

The psychological consequences of caregiving and the cancer care experience cannot be termed as negative or positive as there are evidences for both. There are caregivers who report finding purpose of life, acquiring post traumatic growth after the whole cancer journey, however, a small minority of caregivers also report experiencing anxiety, depression, and trauma before, during and following the cancer experience. Quality of life (QOL) index has also been a potential source of information for the caregiver wellbeing. Some investigators studying the overall wellbeing and quality of life of caregivers of stem cell transplant patients demonstrated that caregivers experienced a decline in their QOL (El-Jawahari et al., 2015).

Reducing visible stressors has undeniable benefits, but individual's inner awareness and degree of awareness of their need for care must not be ignored or side-tracked. These perceptions, demands and internal self-evaluations formulate one’s subjective need for care or caregiver burden. This phenomena is a joint phase of significant impact on the quality of life of caregivers, depression and anxiety as well as distress and coping mechanisms according to extensive research (Donaldson et al. 1997; Schulz et al., 1995).

Campbell and colleagues (2008) later confirmed this finding in a study that assessed multiple variables of caregiving experience wherein subjective caregiver burden has repeatedly been considered the major key sign of caregiver stress. Around the same time, Folkman and Moskowitz (2008) discovered that under stressful situations, caregivers experience both positive and negative emotions. They advanced the idea of meaning-focused coping, according to which those who provide care can find mental and emotional support at trying times by adhering to their belief systems, values, and existential aims thus initiating positive emotions and wellbeing. Folkman and Moskowitz discovered that meaning-focused coping is an intrapsychic process of 1) reallocating priorities and duties in light of changes, 2) setting goals that trigger or stimulate a sense of proficiency and competence, 3) discovering benefits in nurturing, 4) being mindful of the advantages and benefits of providing care, and 5) giving ordinary events positive meaning. In his study, Folkman (2008) further acknowledged that caregiver stress processes has meaning focussed coping mechanisms along with negative evaluations to restore physiological and psychological resources during distress and trauma.

## Care culture in India

Although the complexity of the caregiving burden and coping mechanisms is not limited to any one particular culture or geographical area, there are certain significant and unique factors that have an impact on the caregiving experience in Asia, specifically India. Asian societies place a greater emphasis on the family, with members of the family expected to uphold the virtues of compassion, loyalty, filial responsibility, respect and dedication. (Chan , 2010; Funk, 2011).

A study done in Singapore, a multi-ethnic country with a large Chinese population, found that family carers who internalised and valued societal expectations over their own well-being were more likely to experience internal conflict and struggle to maintain their mental health, family ties, and caregiving responsibilities. (Ng et al. 2016).

Younger Asian generations no longer see complete submission to the family as instrumental values in a modern, globalised society, which is supported by the changing attitudes towards such Confucian rules (Lum et al., 2016). It would be helpful to learn more about how these complexities might manifest in the motivations of a family caregiver. By addressing the following research issues, this study hopes to advance and add to the corpus of knowledge already available for Indian family care providers: 1) What drives Indian family caregivers internally—that is, how do they unwittingly incorporate their ideas and values into their attitudes and behaviours? 2) How could their wellbeing be impacted by these motives and how they react to providing care? 3) In order to improve and maintain carer wellbeing, how might a knowledge of these motives be incorporated into psychosocial interventions?

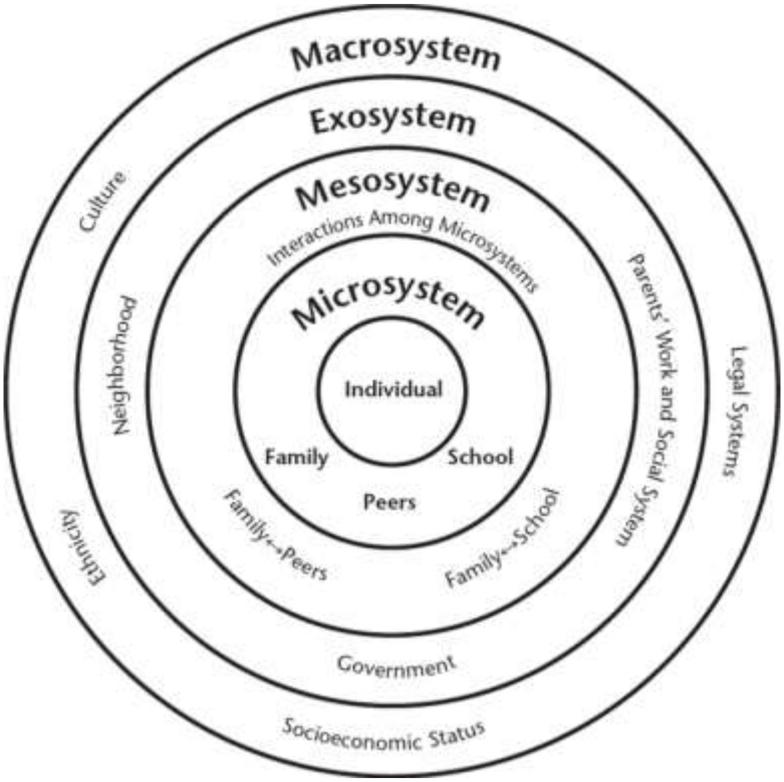
## The Family Ecology Model

The framework of Bronfenbrenner's Family Ecology Model (1979) by Pederson and Revenson was chosen as the supporting theoretical framework for this investigation. The study of the correlated interactions, communication between and within families, individual family members, and their environments is known as family ecology theory (Fiss et al., 2013). This structure of Family Ecology places a greater significance over the bio-psycho-social influences on environment and adaptation of an individual (White et al., 2015).

Process, person, context, and time are the four components of this approach, according to Tudge et al. (2009). The biological, genetic, and individual elements that a person brings to any circumstance make up the "person" component. There are four different parts to the "context" component: The "microsystem" is the setting in which people spend the majority of their time (for example, at home or school); the "mesosystem" is the interaction between "microsystems"; the "exosystem" is a set of indirect influences that have an effect on development even though a person is not physically present there (for example, a mother's work may stress a child out); and finally, there are four other systems. The larger culture or social group that determines beliefs and way of life is referred to as the "macrosystem". A person's developmental history, including the developmental effects of experiences and events, is referred to as their "chronosystem" (White et al., 2015).

The Family Ecology Model has been used to analyse the effects that circumstances and surroundings have on people and families. It has been used to understand a diverse range of events and situations, such as interpersonal conflict, parental divorce, and the adaption of recently single parents among others (Demo et al., 2005). This theoretical framework has also been employed to comprehend the effects of diseases on development in kids with cerebral palsy and primary headache (Fiss et al., 2013). (Napoli et al., 2002). The Family Ecology Model was applied to chronic illnesses by Pederson and Revenson in 2005, although this theoretical framework has not yet undergone a thorough empirical investigation. According to the concept, disease has an impact on daily routines, physiological stress reactions, the distribution of tasks and duties within the family, and family functioning. The efficacy and functionality of families and the wellbeing of adolescents may be affected by the interactions between these systems. These findings support the Family Ecology Model as a potential tool for understanding how family and environment interact with personal traits to influence disease experiences.

Fig 1: **Bronfenbrenner's ecological systems theory**



## Methods

## Interpretative phenomenological analysis (IPA) (Smith et al., 2009)

The study employed the method of IPA. It is a purely qualitative, experiential and psychological research approach which explores in-depth life experiences of individuals and major life goals, detailed lived human experience in their context of environments, and contextual and personal factors affecting the same. According to Smith and Osborn (2007), IPA is particularly used in exploration case of dynamic, contextual, complex, ambiguous, emotionally laden and subjective life areas, when few areas are under explored or when topics of self and identity and personal experiences need to be explored. IPA has also been chosen for the study because it is an idiographic method supremely defined by small sample groups (Pietkiewicz and Smith, 2012; Hill et al., 2009). Because of the small sample size, the researcher is able to provide attention to micro-details. The investigation will sharpen to a large extent due to the inductive nature of the IPA method firmly grounded in the self-accounts of individual participants. For this purpose, the method of IPA would be done by constructing and validating an interview schedule intended to yield an in-depth understanding of the life experiences of the cancer survivors and caregivers during and after the journey of cancer. Also, IPA has been widely used to explore experiences of people with cancer, particularly from the perspective of the ill person including adult (Hill et al., 2009; Holland et al., 2016), child (Griffiths et al., 2011) and adolescent populations (Al Omari et al., 2016), however this method has not been used much to explore the life experiences of family and caregivers of patients (Antoine et al., 2013). IPA has proved to provide detailed examinations of a lived experience through its protocol method (Smith et al., 2009).

IPA focusses on how people make sense of major life experiences. It examines detailed human lived experience, where participants are situated in their context and their personal perspectives are explored. Smith and Osborn (2007) explained that IPA could be particularly useful when the topic of interest is dynamic, contextual and subjective; under-explored and also for topics related to identity, the self and making sense. IPA is, therefore, a suitable method to understand dynamic individual and contextual elements interacting to explore lived experiences. IPA, as an idiographic method is characterised by small samples (Pietkiewicz and

Smith, 2012; Hill et al., 2009). IPA can be used to provide in-depth analysis about a participant's experience.

**Design**

This study used three female cancer caregivers completing semi-structured interviews, who were selected to carry out an IPA (Smith et al., 2009).

The goals of this study are to provide a thorough understanding of cancer carers' experiences, to identify the personal and environmental factors that influence adolescent experiences and help understand how individuals differ in their coping and adjustment mechanisms, to comprehend the protective and healing factors in relation to the recovery process, and to assess the potential application of the Family Ecology Model to understanding survivorship experiences.

**Table 1: Demographic details of cancer caregivers**

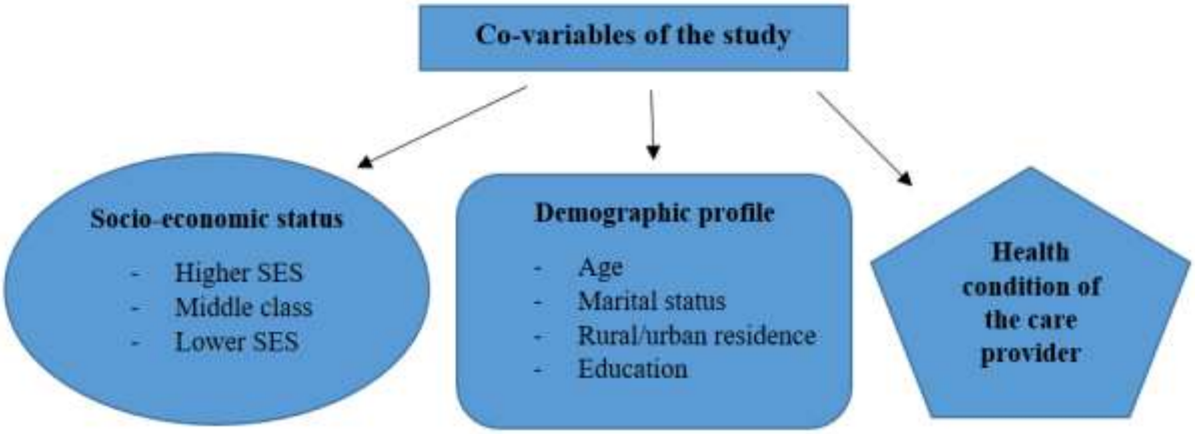
| Caregiver identifier | Gender of the caregiver | Age of the caregiver | Relation with the patient | Patient gender | Patient cancer type | Time since diagnosis (years) | Length of the interview |
|---|---|---|---|---|---|---|---|
| SS | Female | 25 | Child | Male | Oral cancer | 7 years | 1:15 hr |
| RB | Female | 26 | Niece | Male | Gastric cancer | 6 years | 1:10 hr |
| AN | Male | 25 | Child | Male | Gastric cancer | 7 years | 1:04 hr |

**Recruitment and sample**

Participants for the study were recruited via the following method. First, cancer caregivers visiting the cancer specialized hospital were provided with information regarding the objectives and rationale of the study. There were other potential participants who were self-recruited through the online mode of data collection for screening. This study was fully approved by the head oncologist at the hospital. All potential participants received information sheets and consent forms. Careful consideration was given to the ethical implications of this study as the researcher was aware of the sensitivity of the topic addressed.

A total of 75 cancer caregivers were considered for the pilot screening, out of which three participants with homogenous backgrounds agreed to complete semi-structured interviews with the researcher. Three interviewees were purposefully selected for this analysis, as they provided the most detailed accounts of how adult female contexts and ecologies had an impact on cancer experiences. These participants were selected also because they shared similar demographic profiles, age and gender (Pietkiewicz and Smith, 2012). They were also going through the developmental transition of entering their middle age and all the participants were employed at the time of detection and diagnosis.

**Fig 2: Co-variables of the study**



## Data analysis

In order to examine the internalised motivations of family caregivers in providing care for a ailing family member, this study used an interpretive phenomenological analysis (IPA), a qualitative research technique to shed light on how a person perceives and interprets a phenomenon. (Smith, 1998). The researcher used IPA to use a method of data reduction and data reconstruction to find reflections on reasons for caregiving that naturally appeared throughout the interview transcripts.

Firstly, the qualitative interviews of the participants were transcribed by the researcher. The transcripts of the participants were then line by line coded in order to result in descriptive themes, categories, concepts and data interpretations. Further, the themes and codes were repeatedly refined in order to identify similar codes to achieve subthemes, cluster themes and finally emergent themes. In the end categories, emergent themes and subthemes were mapped and supported from quoted responses from the transcripts and participant responses were interpreted. The themes that emerged from the data were validated by experts from the field and inputs were incorporated.

**Table 2: Explanatory Variables**

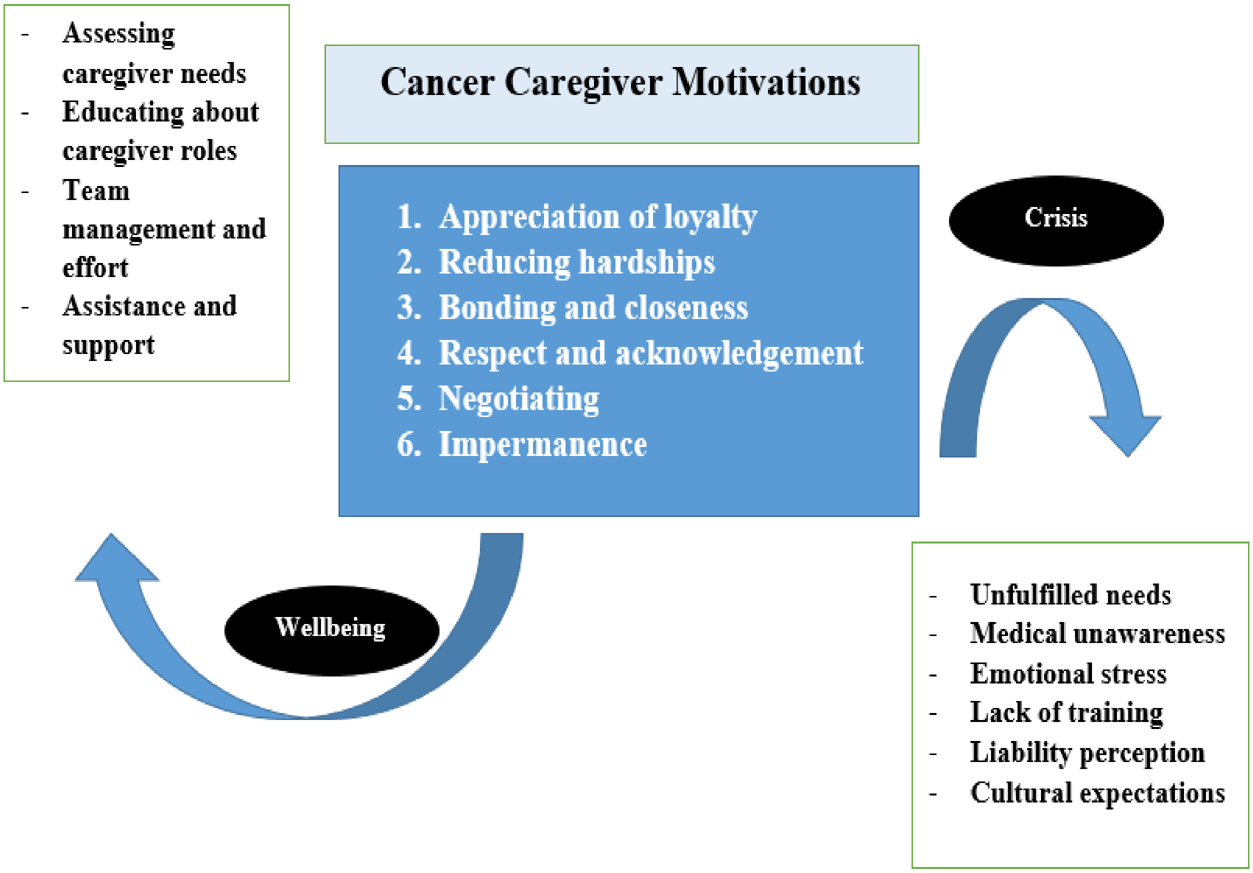
| **Caregiving hours** | **Caregiving activity** | **Relationship proximity with the patient** |
|---|---|---|
| The analysis of adult caregivers in the household included a series of questions regarding the amount of time spent on caregiving tasks. Adult caregivers were surveyed on their caregiving time, categorized into "part time" (less than 40 hours per week) and "full time" (more than 40 hours per week). | Care activities are categorized into five types:<br>1. Daily life activities<br>2. Medication management<br>3. Socio-emotional care<br>4. Finances and monetary regulations<br>5. Occupational activities such as cleaning, cooking, laundry etc | The data categorized primary caregiver-care recipient relationships into groups:<br>1. spouse/partner<br>2. Parents<br>3. parents-in-law<br>4. brothers/sisters<br>5. children<br>6. relatives<br>(gender distinction was not possible due to data limitations) |

## Findings

In the current study, Figure 1 represents the Caregiver Motivation model for Indian Context along with the motivation determinants. The themes are as follows: 1) Recognition and appreciation of allegiance and loyalty (caregivers were inspired to follow their support duties and presumed roles in order to avoid remorse later), 2) Weakening and reducing the pain, hurt and agony (caregivers were motivated to relieve their family member's ache and hardships), 3) Experiencing the bonding and closeness (caregivers were highly motivated to spend quality time together with their loved ones), 4) Maintaining appreciation, regard, respect and acknowledgement (caregivers were motivated to express their gratefulness to their family member by caregiving), 5) Negotiating and traversing the shift and substitution (caregivers were motivated to acclimatize consequently to changes in the illness prognosis) and 6) Adjusting to impermanency and temporality (caregivers were motivated to respond consequently to their family member's illness trajectory).

The model depicts the beliefs, values, and objectives that the caregiver incorporates into their daily lives; each motivation is proposed to have an impact on how the care provider interprets their role, ultimately resulting in either the enhancement of their wellbeing, or a decrease in caregiver wellbeing. The study also includes a list of wellbeing determinant factors that either the carer has or experiences. The six caregiving motivations are thought to be evaluated favourably by the caregiver under the influence of the Wellbeing Determinant, which is characterised by the carer's sense of control, self-empowerment, and their experiences.

**Fig 3: Cancer caregiver motivation Model**



## Discussion

The study elucidates the importance and significance of internal subjective motives, needs and role shifts of family caregivers within the Indian Context. While the multi-faceted nature of caregiver burden and caregiving coping is not limited to any particular cultural background, there are some unique factors that shape the Asian caregiver experience. Family is at the heart of Asian culture, and family values and expectations are deeply embedded in Asian culture. Family members are expected to demonstrate filial piety, filial responsibility, and filial love.

While in the process of being interviewed, a cluster of motivation centered responses surfaced spontaneously, which indicated how internal processes like inherent compassion and internal motivation are intertwined with caregiving attitude and actions. The Caregiver Motivation model depicts the impact on caregiver wellbeing as well as the determinants the themes were based on, as shown by the responses of the caregiver participants.

### Cancer Caregiver motivations

Caregiving is a long-term unpaid task that can have a negative impact on a caregiver's physical or emotional health, as well as financial stress, anxiety, and social isolation. The relationship quality between a caregiver and a care recipient is a key factor in determining whether a caregiver's role is burden-bearing or not. If there is conflict between the two, it can have an indirect impact on the caregiver's burden. Gender-specific differences in burden can be seen in the involvement of women in domestic activities and economic participation, which in turn lead to poorer relationship quality with the care recipient, which in turn can be a contributing factor to poor physical and psychological health. Furthermore, the general health of a caregiver is significantly impacted by the type of illness that is affecting the care recipient.

As life expectancy and health transitions increase, the global disease burden has gone up to 23% because of chronic and long term health issues among older adults. India is on the verge of becoming an ageing society, and with an increasing share of chronic diseases among older adults, we'll need care services in the near future (Ajay et al.,2017). In the case of palliative care, we'll need more than just in-house care. In traditional Indian and other South and Southeast Asian societies, caregiving is more common where the family is the main source of care and filial piety is really strong. For a long time, this cultural system has encouraged and obligated co-residents to be informal caregivers, and in Indian households, the primary caregiver is usually the spouse, along with the younger generation of the family. This means that the age of the caregiver is very wide. But formal or paid care for the elderly has a higher economic burden for both the care recipient and the family, especially in the absence of a proper social security system.

## Influence of Culture on Internal Motivation

Some themes highlighted cultural undercurrents that showed how Indian ideals had been ingrained in the intentions of family caregivers. Cancer caregivers expressed the desire to do so through practical ways, such as giving their family member medication, and expressed grief when such measures were not practicable in their reason for attenuating suffering. This is consistent with Asian culture, which favours using practical means to express concern for one's family members. (Ho et al, 2017). Family caregivers showed the importance of family loyalty, as well as cultural beliefs about karma and past lives, within their attitudes towards caregiving in their motivation for Maintaining respect and acknowledgment (Jiao & Hussin, 2018). Last but not least, family carergivers mentioned the value placed on strong intergenerational ties and longevity for their elders in their motivation for Adjusting to Impermanency. (Ho et al, 2013).

In Singapore, a multiethnic society composed primarily of Chinese, a study revealed that family caregivers that internalized and placed societal expectations as a priority over their own well-being were more likely to experience internal conflict and struggle to maintain their mental wellbeing, family ties, and caregiving responsibilities. This finding is in line with the changing attitudes towards such traditional Confucian values in Asia, where younger generations no longer view absolute submission or obedience to family values as essential in a modern, globalized society. This study seeks to expand the existing body of knowledge on the motivations of family caregivers in India by addressing research questions such as: what are internalized motivations? How could these motivations influence the response to caregiving and have an impact on caregiver wellbeing? How can a knowledge of internalized motivations be incorporated into psychological interventions to improve and maintain caregiver wellbeing?

### Benefits and limitations of providing care

These motivations led family caregivers to exhibit the propensity for benefit-finding and benefit-reminding even as they witnessed their loved one's suffering and impending death; adaptive goal processes in adjusting their expectations and aspirations in accordance with their family member's physical condition and prognosis; rearranging priorities in an effort to make the most of the time they had left with their family member; and infusing ordinary events, both past and present, with meaning. (Campbell et al. 2008). Thus, these motivations would be significant factors in the caregiving journey due to their ability to provide meaning in tough and trying situations.

Contrarily, a similarity between the caregiving attitude and intrapsychic strains proposed by Pearlin and colleagues (!990) in their landmark Stress Process Model was further discovered. When the caregiver's self-concept is damaged as a result of the long-term nature of providing care, intrapsychic stresses develop. 1) Role captivity, in which the carer feels stuck in his or her role whether intentionally or unintentionally, 2) The loss of self, in which the carer loses their sense of self as a result of becoming entangled with the patient, 3) perceived poor competence, in which the carer does not recognise the expertise and importance of the task they perform, creating a sense of powerlessness.

The caregiving duty and responsibility are so sudden and abrupt that it may cause caregivers to feel the symptoms of strains and stress very soon in the journey of providing care. It may further result in mental breakdowns, emotional distress, depression and anxiety spouts as well as increased irritability, ultimately resulting in caregiver burden.

### Cancer: Caregiver burden and Hope

According to National Cancer Institute (2018) there were potential risk factors for caregiver burden found out which were as follows:

**Gender**: In a survey study it was suggested that female gender is a confirmed risk factor for increased burden for caregiver (Kim et al., 2015). Research also showed that hope and perceived fulfilment of support needs were found to be most significant protective factors against burden for both genders. Along with this it was suggested that women who were employed or who used emotion-focussed coping strategy were more likely to perceive "burden" (Schrank et al., 2016).

**Age**: Research suggests that caregivers of all ages often feel unprepared, have inadequate knowledge and awareness and report little guidance received from the medical professional team of oncology about the patient care (Scherbring, 2002). It is proved that older caregivers are more susceptible due to possible presence of co-morbidities, fixed incomes or decreased social support. They might also show negligence towards their own health care needs and harm sleeping and eating patterns. It is therefore common for caregiving by older people to lead to poor physical health, show symptoms of depression, and even increased mortality (Given et al., 1993; Schulz et al., 1999). However, research indicated that younger caregivers can multitask, in order to handle work and family life responsibilities and roles, and make significant sacrifices and middle aged caregivers typically worry about work interruptions, absence from work, and reduced productivity (Cameron et al., 2002; Given et al., 2006).

**Race and ethnicity**: In a meta-analysis study done by Pinquart and colleagues (2005), it was suggested that Asian American caregivers were found to spend more hours of caregiving, use lower levels of formal support services and fewer financial resources, had lower levels of education, and reported higher levels of depression in comparison to other subgroups such as Hispanic, African American caregivers. Studies also reported that Asian American caregivers refused outside help because they "felt too proud to accept it" or "didn't want outsiders coming in" (Li, 2004). A similar hospice study involving Asian Americans, also found lower rates of hospice enrolment by Asian American families due to the family reluctance in discussing the disease, their beliefs about death and bad luck. It is important to note here that avoiding discussions related to disease and escaping from sharing the diagnosis and information with the patient can add onto the caregiver burden (Ngo-Metzger et al., 2003). More so, it was also indicated that Hispanic and African American patients and caregivers tend to underutilize the community health resources such as counselling and health support groups, home care, residential care and hospice care services (Guarnaccia and Parra, 1996). Kovinsky and colleagues (2001), in their study reported that decision of the minority caregivers to show reluctance towards home nursing services for their loved ones was consequently associated with increased financial, social and psychological burden.

**Socioeconomic Status and employment**: Research suggested that caregiving can place high financial burden on the caregivers and this financial strain may place low income families at risk of treatment noncompliance or making treatment-related decisions on the basis of income (Hayman et al., 2001). Cancer treatments have proved to impose economic burden on the families of the patients. A study involving cancer survivors concluded that about 29% of caregivers had to make extended employment modifications such as change of duties and employment status; there was a 23% decline in work productivity reported by 70 caregivers of advanced cancer patients (Mazanec et al., 2011); and 69% of caregivers reported adverse impact on work life (Grunfeld et al., 2004; De Moor et al., 2017).

**Role strain**: Role strain tends to emerge when the functions, duties and responsibilities of one socially defined role conflicts with the duties and responsibilities of another role (National Cancer Institute, 2018). The caregiver can be possibly performing multiple roles at the same time and might receive demand in each area or role. Multiple caregivers of cancer patients might compete for caregivers' physical and emotional resources (Kim et al., 2006).

**Site of care**: Unplanned change of places during or after the treatment (such as in case of sudden hospital re-admission), the caregiver burden tends to increase manifolds. Investigators have reported that symptoms management can reduce such sudden transitioning in order to reduce caregiving duties (Geddie et al., 2016). A qualitative study done on 12 caregivers and 12 patients about the challenges faced in transitioning from hospital to home identified four primary themes such as: Ongoing concerns related to disease and its treatment, Needing timely help, Resuming control and normality and Appreciating the care transition. It also found out the causes of stress of transitioning such as the need to deal with symptoms, and uncertainty about prognosis and disease progression (Rocio et al., 2017; Ang et al., 2016). Hence, site of care is a potential cause of caregiver burden

## Quality of life of Caregivers

As explained by Glaichen (2004), the role of the patient caregivers is multifaceted and requires guidance and mentoring. Cancer caregivers are more likely to report more psychological concerns as compared to patients. Moreover, cancer caregivers who are spouses tend to seek greater amount of information related to family care and psychological support. (Chen, 2014).

Psychological distress is negatively associated with Quality of life of an individual (Smith, Bellizzi, et al., 2013). Research supports that adolescent cancer survivors report to have a worse Quality of life and exhibit a declined mental and physical health as compared to child cancer survivors (Kazak et al., 2010; Wei-Wen Wu et. al., 2015).

Caregivers can be termed as “hidden -patients” and most times require similar empathetic treatment and like those given to the patient (Braun et al., 2007). According to Kim and Given, (2008), Cancer has lasting effects on the Quality of health of both caregivers and patients (Northhouse et al., 2012). Even after the treatment and while in remission, majority of patients need continual specialized services and support (Warapornmongkholkul et al., 2017) whether in inpatient setting or ambulatory or home settings (Ministry of Public Health in Thailand, 2013; Given et al., 2001).

Caregivers, mostly report feelings of being under preparedness when cancer patients are suggested in home care services (van Ryn et al., 2011). Some caregivers might leave jobs and acquire extra help to provide patient care, which again deals with heavy economic burden on top of the already venturing treatment costs (Yabroff et al., 2011; Warapornmongkholkul et al., 2017).

**Survivorship:** The available evidence indicates that a significant minority of caregivers continue to experience the unmet needs related to cancer journey even after treatment and during the survivorship phase. Longitudinal studies done on psychosocial, financial, and occupational impact of unmet needs of caregivers, suggested that- the proportion of caregivers reporting any unmet need decreased from 50.2% at 6 months to 30.7% at 24 months, the most pressing unmet needs were related to concerns about recurrence, reducing stress in the survivor’s life, and understanding the survivor’s experience and unmet needs were negatively associated with caregivers’ well-being (Girgis et al., 2013).

Psychological distress is negatively associated with Quality of life of an individual (Smith, Bellizzi, et al., 2013). Research supports that adolescent cancer survivors report to have a worse Quality of life and exhibit a declined mental and physical health as compared to child cancer survivors (Kazak et al., 2010; Wei-Wen Wu et. al., 2015).

Studies suggest that caregiver distress was predicted by lower optimism, higher unmet needs, and shortened time to patient death (Butow et al., 2014). Evidence also indicates that in the last 6 months of the patient's life, high unmet needs of the caregiver were related to balancing work with caregiving demands and managing emotions about poor prognosis.

In a study using supportive care needs survey (for caregivers) done by Oberoi and colleagues (2016) on 196 caregivers of renal carcinoma, investigators demonstrated that 64% of caregivers showed at least one unmet need, 53% exhibited three or more unmet needs, 29% showed 10 or more unmet needs. The study also showed that 30% of caregivers reported unmet needs related to health care services, 23% for work and social life, 30% for psychological and emotional needs and 18% for unmet informational needs respectively.

Sklenarova and colleagues (2015), in their survey study done on 188 patient-caregiver pairs, found that the majority of caregivers were females with the average age of caregivers fount to be 57.8 years. It also indicated that unmet needs of the caregivers were modestly associated with caregiver anxiety. A similar 166 lung cancer patient-caregiver dyad study done in Taiwan found that the top ten unmet needs were information needs (Chen et al., 2016).

## Implications and recommendations

It indicates that maintaining one's drive and inherent joy in caregiving depend on one's ability to fulfil their feeling of self-determination (Dombestein and colleagues, 2019; Milyavskaya & Koestner, 2011; Weinstein N, Ryan, 2010). According to the present study, caregivers are motivated by factors that may either enhance or detract from their patients' welfare. However, our findings also show that motivation and inherent personality traits have a key role to play in self-determination.

Cancer caregiver interventions should be provided in a way that is relatable to the individual's culture. This can be achieved by emphasising how these mediators will support family caregivers in improving their practice through greater competence, a sense of control, and meaning-making, as well as enriching their intergenerational family ties through talks that centre on tradition and values.

## Limitations and future directions

The study was able to highlight the significance and importance of caregiving responsibilities in Indian Context via the collected and analysed responses of the participants. However, the participant interview data can be further analysed and incorporated as a future step in the future caregiving researches. Many unexplored answers and areas can be dwelled upon using the current research as a base study for Indian character and familial culture. AD deeper understanding of the issue with a stronger representation of the desired population such as gender, age, and geographical area can successfully provide significant insights regarding the motives and human bonding, which will undoubtedly result in supporting therapies and interventions.

## Conclusion

Cancer care journey is one with a lot of challenges, fear, uncertainty, trauma and belief, where fear and failure are peaks which cannot be skipped by the patient nor the caregiver. The duty of caregiving and the severity, pressure and strain of a cancer care journey, may soon turn the motivation of a caregiver into a phase of distress and moral bondage, irrespective of the perseverance and inherent motive of those who care. However, it is that time when the caregiving process turns exhaustive and weary, when the strength to regain consciousness and achieve a sense of autonomy, choice, will and action surfaces. This is when, certain individuals are able to bounce back resiliently, nurture and respect the relationships, accept the flaws and admire the beauty of humanity. And compassion, while respecting their culture and societal bonding.

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