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“They will think we are the Cancer Family”: Studying Patterns of Cancer Disclosure and Communication among Indian Immigrants in the United States

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“They will think we are the Cancer Family”: Studying Patterns of Cancer Disclosure and Communication
among Indian Immigrants in the United States

by

Kanan Mehta

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
with a concentration in Bio-cultural Medical Anthropology
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Keywords: cancer, disclosure, Indian immigrants, providers, health communication, caregivers, therapy
management

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DEDICATION

To my participants who were kind and brave enough to share their stories.

To Simi, I hope you can see and hear your story from the pink sky above.

To Papa, my gift and tribute to you.

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ABSTRACT

Studies of Indian immigrants in Western countries show that the rates of cancer increase significantly within a generation in the host country. The negative social perceptions associated with health outcomes of cancer often perpetuate limited disclosure regarding the diagnosis of cancer among patients and families. This can result in disrupted communication in clinical settings, while causing increased stress among patients and caregivers. These findings demonstrate the need for studying lived experiences of cancer-related illness and its impacts on social relationships in the domestic and public sphere.

This study explored cancer disclosure and communication among Indian immigrants in the United States and their subsequent impact on decisions regarding treatment. Additionally, this study explored the relationship between biomedical ethics and their intersection with cross cultural models of health and caregiving.

Most anthropological studies on cancer have focused on cultural attitudes regarding disclosure of the diagnosis among patients from diverse populations. However, there is limited research on Indian immigrants with regard to cancer. Given the high susceptibility of certain cancers among Indian immigrants, there is a lack of an effective patient-provider communication approach that accounts for the connection between cancer disclosure, caregiving and therapeutic decision making in the Indian immigrant population.

This qualitative study recruited 35 participants (n=35) which included in-person and phone interviews with cancer survivors, family members and health care providers. The majority of

participants were based in metropolitan Atlanta, Georgia, although a few participants were also recruited from other cities in the United States.

This study expands on the understanding of social and cultural processes that shape cancer communication among Indian immigrants in the United States. It fills gaps in anthropological literature regarding cultural models of health associated with cancer and its social and therapeutic implications on patients and caregivers. Furthermore, it informs the collective experiences of illness shared by patients and families, and the variation in cancer disclosure practices among Indian immigrants. The study's findings emphasize the need for a culturally sensitive model of bioethics and patient-provider communication in dealing with cases of cancer in this population. Additionally, the study informs perspectives on cancer communication among other immigrant populations with similar cancer-related disclosure practices.

CHAPTER ONE: INTRODUCTION

“They will think we are the cancer family.” I heard these words as I sat across an elderly family member. I had been asking questions about my paternal grandfather, who had passed away due to cancer. There had been other relatives who had lost their lives to the same disease. Similar sentiments had been expressed by an aunt, whose daughter had also been diagnosed with cancer and was undergoing chemotherapy. My aunt was concerned that there would be judgment from outsiders regarding cancer, a pattern in our family, and hence was reluctant to talk about it. One of my cousins – who eventually shared her own diagnosis of cancer with me – expressed feeling extremely baffled since the diagnosis defied everything that she knew about the disease: she did not smoke or drink alcohol, was a vegetarian, and maintained a normal weight.

The first two experiences left me a little surprised. While the notion and practice of attaching social meanings to an illness was not alien to me, especially as a student of anthropology, it had finally hit home. For some reason, I had assumed that such notions surrounding cancer were gone with my grandparents. Perhaps, death, more than dying, has the quality of bestowing a sense of finality to everything that it touches except what is intangible, which in this case was the meaning and legacy of cancer and its experience. In my cousin’s case, I could understand how the tendency to explain the cause of a disease or to question its occurrence can become a form of consolation, particularly when an individual encounters the possibility of suffering a health condition that can be terminal.

Hence, I had witnessed various cases among family members and the larger social circles where cancer was too dreaded to be even spoken about, even to the patient. People would often refer to a diagnosis of cancer as *bimari*, which simply meant “sickness,” and the patient as *bimar* implying the one who is “sick”. The word itself was never mentioned, as if it had a life of its own even outside the body. The reactions of silence surrounding cancer and the stigma attached with the label of being perceived as “the cancer family” formed the basis for my interest in exploring how cancer is understood and articulated. However, my intention with this research is to not present a stereotypical and rigid impression of cancer as an illness that is mainly dealt with silence and secrecy. If anything, this research present show individuals in the community cope with cancer. It attempts to present the various dimensions of the lived experiences of cancer on the social spectrum of human existence that includes stories of hope, courage, agency and resilience.

Portrayals of Cancer in Indian Media

Many illness are linked with various social meanings and cancer is no exception. Apart from witnessing several cases of non-disclosure of a cancer diagnosis, I realized that similar examples were prevalent in movie plots and the popular culture that have reinforced and reaffirmed the hesitation that has existed in talking about a cancer diagnosis. Hence, these examples situate the topic of cancer disclosure within a larger cultural context. In 2012 and 2017, two famous Indian movie actors, Rajesh Khanna and Vinod Khanna passed away due to cancer. Both actors had been prominent celebrities where the former was often referred to as the “Clint Eastwood of India” due to his defined cleft while the latter was often hailed as the “first superstar of India”. In both cases, their diagnoses of cancer were barely mentioned in the media and were

mostly revealed closer to or after their impending deaths. Similarly, there had been other actors who had passed away due to cancer but there was never any discussion of their diagnosis or illness. To be fair, these actors also belonged to an era where being inaccessible and enigmatic added to the charm of being a movie star. However, the perceived notion of the “deadliness” of cancer and its impact on the body certainly played a role in nearly the inexistence of the discussion of the illnesses of these people who otherwise were always the center of attention and the subject of avid public consumption among their cult followers.

Similarly, Indian movies have featured several plots where the silently self-sacrificing protagonist was diagnosed with cancer but did not share his diagnosis with anyone including family members. Instead, the protagonists in such cases often put their health and emotional concerns aside to devote themselves to taking care of their loved ones, ensuring that their duties and responsibilities were complete and that they continued being productive members of society before their impending death. These Indian cinematic tropes resonate with the themes of non-disclosure of cancer and equating silence around illness with resilience.

Additionally, anti-smoking advertisements that were routinely screened in cinema halls painted an extremely grim, dark and fearful picture of the consequences of smoking. However, there has been a gradual change on the discourse of cancer in Indian social media and public platforms. A few notable Indian celebrities have attempted to facilitate a more open discussion on cancer on social media platforms by sharing their own experiences of cancer. Tahira Kashyap who is a film director has shared her experience of cancer along with other prominent actors such as Sonali Bendre and Nafisa Ali on several media outlets. Likewise, some of the present day Indian advertisements have tried to present a positive and inclusive portrayal of a cancer

survivor. For instance, one of the advertisements by a hair oil brand shows a woman who has lost hair due to chemotherapy as receiving acceptance and support from her colleagues.

In addition, non-profit organizations such as “Chai for Cancer” by the MAX foundation have initiated similar initiatives with patients/survivors, families and health professionals to present their narratives of cancer. Similarly, Indian volunteers have taken the efforts to support housing efforts for cancer patients in Mumbai, India through the efforts of U.S. based organization Access Life America. While these instances are a handful, they do indicate the willingness to be more open regarding discussions on cancer in select Indian communities in India and the United States. Thus, these counter narratives along with my own experiences regarding how a diagnosis of cancer is framed and understood among Indian immigrants has formed the foundation of this study.

Framing the Study in Context of Cancer Disclosure

According to Ghoshal et. al (2020) while western medical care emphasizes the full disclosure of a cancer diagnosis to the patient, this is not unanimous in countries such as Japan, Tanzania, Italy and India. Cancer communication is a complex process which is not merely limited to the transfer of information but also involves integrating the preferences of patients and family members to avoid demoralizing patients and safeguard a therapeutic partnership with health care providers (Ghoshal et. al 2020).

Additionally, physicians have also differed in their opinions on cancer disclosure in depending upon the cultural and regional domain of medical practice. For instance, physicians in Tanzania, Italy and Japan tend to approach cancer disclosure on an individual basis depending upon the following factors. Physicians in Tanzania tended to consider socio-economic

circumstances such as availability of insurance and resources for the patient in their decision to disclose while physicians in Italy and Japan often take into account the wish to access medical information or the perceived negative effects of disclosure on patients and family members (Ghoshal et, al 2020). These findings show that cancer disclosure is a complex process that collectively impacts the illness experiences in patients and families and is a significant part of the therapeutic process.

In consideration of these factors, this study accounts for the collective experiences of patients/survivors, caregivers, and health care professionals regarding cancer among Indian immigrants in the United States. This was a qualitative research study that was conducted among 30 (n=30) patients/survivors and family members, and 5 health care professionals (n=5). Most of the participants were from metropolitan Atlanta while a few other participants were included from other cities of the United States to achieve an optimum sample size.

Key Observations Prior to Research

When I embarked upon this research, I encountered a few opinions from some of my Indian friends based in the United States and India when I was trying to recruit participants which provided me an insight into the different assumptions that these individuals had towards cancer disclosure. The first opinion was that this was a topic to be researched only among people with low levels of education. The second opinion was that this research only applied to rural areas in India which were presumed to be inhabited by low income populations. In other words, the lack of cancer communication was perceived to be present among individuals who resided in rural areas, had a low socio-economic status and low education levels. These remarks also implied that the topic of this study was not applicable to Indian immigrants in the United States,

since they were perceived to have basic to advanced education where many immigrants at least own a bachelor's degree (Atlanta Regional Commission date *n.d.*).

The second assumption suggested that this kind of research was best suited for Indians residing in rural areas of India. In other words, the topic of cancer disclosure and cancer communication could not be applied to Indian immigrants whose immigrant profile was largely synonymous with their educated, middle class counterparts in urban India. These assumptions demonstrated the tendency to presume that a dialogue about cancer communication and disclosure did not “fit” the lives and experiences of educated Indian citizens in urban areas of India, let alone the ones residing in cities in the United States. They illustrated that somehow education, upward mobility and residence in urban areas collectively signified social privilege that had an evasive effect on the experience of chronic illness.

Although dissuading at the beginning, these statements relayed certain preconceived beliefs about cancer, its chronicity, and whose narratives of cancer illness deserved to be heard based on their presumed social, educational, financial and residential status. These impressions partially stem from the notion that limited disclosure regarding a cancer diagnosis only prevails in rural areas of India due to lack of education and awareness about cancer, although structural inequities and inaccessibility to medical amenities are often the underlying causes (Treloar et. al 2013). Therefore, these assumptions mislabel the experiences of cancer disclosure and illness as ignorance among the “uneducated and the rural” in India while similar experiences of cancer are presumed to be not even present among Indian immigrants.

In my experience, this is partly due to the speculation that immigration to a western country represents progress, affluence, sophistication and open-mindedness, all of which do not align with concealing a diagnosis of cancer. These experiences show how the stereotype of the “other”

is perpetuated in social spaces through which we misrecognize people (Mitchell in Mirzoeff 2005) and discount illness experiences. This renders the illness of cancer in urban social spaces invisible and its narrative as non-existent, perpetuating non-disclosure of cancer where it exists while overlooking cancer-related experiences of individuals who have stories to share. In seeing the issue of limited cancer disclosure as a symptom of ignorance or lack of knowledge, these presumptions do not account for the impact that a diagnosis of cancer has within a family unit which includes the patient, his/her caregivers, dependents and other close family members. With regard to these notions and in exploring the central interconnected issues around cancer disclosure and illness, this study explores the following research questions:

1. How does cancer communication impact illness experiences among Indian immigrant patients and families in the United States?
2. How does cancer related illness influence the division of gender roles among patients and families?
3. How do prevailing biomedical ethics intersect with cross cultural models of health and caregiving?

Overview of Chapters

Chapter 1 elaborates on the experiences and insights for exploring experiences of cancer and cancer communication among Indian immigrants in the United States. It outlines key assumptions that I came across during the onset of fieldwork. In addition, Chapter 1 provides a brief summary of the research questions and methods for this project.

In Chapter 2, I talk about the theoretical perspectives in medical anthropology that have lend support to patient narratives of illness and the conceptualization of the human body as a physical entity as well as a social category. This chapter lays the foundation for studying the collective lived experiences of cancer among patients/survivors and family members in relation to the theoretical applications in the upcoming topical chapters. Also, Chapter 2 highlights the existing literature on patterns of disclosure, cultural diversity in cancer communication and the need for a critical bio ethical framework.

Chapter 3 presents the study design and the methods employed for the study. It provides an insight into my experiences with “studying up” in the field. I also discuss the dilemmas concerning positioning and framing oneself as a “native” anthropologist and how those lines often blur in the field for both researchers and participants. Speaking of dilemmas, I bring attention to the challenges that one faces in navigating the gray area of ethics especially when it concerns studying a sensitive topic. Lastly, I talk about the limitations of the study and the possibility of expanding on this topic to include areas that I have not been able to adequately address due to restraints regarding the length of time, recruitment sample and resources.

Chapter 4 presents participant narratives regarding disclosure of a cancer diagnosis. I talk about certain metaphors that the participants used to describe cancer as a disease which elucidates the reader regarding perceptions of cancer and beliefs about causation in the community. Additionally, it includes a section on the visual representation of cancer in the media as a way to cast a larger lens on where the discourse on cancer disclosure stands in the public domain and how its representation through visual channels serves as an interjection between theoretical applications and perceptions of cancer and cancer communication.

In Chapter 5, I expand upon illness as a collective experience that encompasses lived experiences of individuals diagnosed with cancer and family members. I draw upon the complex relationships that caregivers often share with patients/survivors while both sides undergo their own journey in dealing with cancer. I present the shift in gender roles following a diagnosis of cancer among certain participants. In addition, I underline the role of social support from families and wider social circles in helping to cope with cancer.

In Chapter 6, participants share narratives of using religion and spirituality as coping mechanisms for cancer. Specific religious and philosophical underpinnings such as relying on the notion of karma and reincarnation as a way to accept illness and aim for healing irrespective of whether the healing was related to the illness, impending death or loss are some of the key narratives in this chapter. Participants also outline the transition in religious and spiritual philosophies that occurred for certain participants while for others it was unchanged.

Chapter 7 presents the outlook of health professionals regarding cancer disclosure. It underlines the connection between cancer disclosure patterns and the institutionalization of ethics under the western bio medical system. This chapter traces the evolution of the bioethical framework in medical science and patient care while reflecting on the cultural notions of justice. The chapter reflects on the challenges associated with universal bio ethics while dealing with cross cultural perspectives on patient agency and decision making especially in context of cancer.

Finally, Chapter 8 presents a summary of the research findings and outlines the applied implications of studying cancer communication with the anthropological and public health framework. It underlines the significance of communication among patients and families while arguing for acknowledging the existence of diverse cancer disclosure patterns that affect patient

and provider communication. Additionally, the chapter is a prelude to future steps regarding further exploring the topic of cancer communication and treating this research study as a starting point for questions and facets that still need to be explored.

CHAPTER TWO: THEORETICAL FRAMEWORKS

Introduction

The theoretical frameworks chapter has been divided in two sections. Section I outlines the historical and literary perspectives on explanatory models of illness, perceptions of cancer, and gendered experiences of cancer. In addition, it presents a snapshot of the role of agency and religion in dealing with cancer fatalism, and illness in general, through examples of select studies on the topic. Section II elaborates on cancer disclosure, the emergence of “therapy management groups” and the ways in which family members and health care providers form part of this dynamic. Finally, the section on bio-ethics and political economy of hope underline the connection with cancer communication and collective decision making. Together, the literature and theoretical standpoints in Section I and II demonstrate the interconnectedness between cancer communication, disclosure and the lived experiences of cancer illness for the individual and their family members.

Section I: Theorizing Cancer

The literature on cultural and historical depictions of cancer offers several metaphors to symbolize the chaos and uncontrollable change commonly associated with cancer in various cultures (Hunt 1998; Weiss 1997). These descriptions of cancer also highlight the negative social perceptions that have affected communication and disclosure. In addition, these descriptions

elucidate the body as both a physical and social actor in the lived experiences of cancer. According to Cassileth, “Cancer evokes the unique dread of horrible death because it is associated with the wisdom of the body gone awry which leads to a subconscious attempt to replace chaos with order, and give meaning to trauma” (in Hunt 1998). Hence, when the “organization or wisdom” of the body dispels into chaos, it disrupts the body’s internal balance resulting in gradual destruction which requires medical intervention. Similarly, Weiss refers to a body afflicted with cancer as a “pathology of the postmodern body in late capitalism” characterized by “rapid and flexible change.”(Weiss 1997). The immune system of the body is synonymous with “globalization” as an “interconnected” system that is “self-regulating,” but becomes disrupted with cancer (Weiss 1997).

Cancer is posited as the ultimate deception of the body to itself. Yet, this also presents an “existential dilemma,” in which the “other” gets inside the “self” (Panourgia in Hunt 1998). Contextual representations of cancer through imagery and language provide an insight into the representation of cancer as a symbol of doom and death and its subsequent association with the culture of silence. The Greek word *karkinos* coined by Hippocrates and synonymous with *cancer* in Latin is depicted as multiple fingers emerging from a central growth similar to the shape of a crab (Cantor in Kozikowski 2005). Similarly, the video game “Pacman” shows an “alien” devouring its victim’s body internally and emerging from its stomach like a “hidden passenger” (Weiss 1997). Thus, the symbolic representation of cancer has been entrenched in metaphors of contamination and infection.

Apart from literary metaphors, cancer garners an extremely negative perception given the high mortality rate, and relatively increased difficulty in treatment and prevention (Weiss 1997: 457). The taboo regarding cancer manifests on various levels in a person’s life and in the overall

society. For example, fear, denial, disfigurement, pain and disability significantly impact an individual's lived reality. Therefore, stigma personifies a socio-cultural life outside of its abstractedness which encompasses intersecting categories of the physical body and the social self. In addition, moral reasoning is associated with causal explanations for cancer along with stigma (Hunt 1998: 298). Since serious illness disrupts normalcy of life, it threatens its existence by provoking moral introspection (Good in Hunt 1998: 299). Therefore, behaviors such as "adultery, hedonism, domestic violence, promiscuity" are equated with themes of purity and danger, as well as good and evil, as possible causes of cancer (Hunt 1998: 298).

In addition, "situations, events and conflicts can be understood as products of a series of political and economic events across time and space rather than as isolated phenomena" (in White 2009: 24). The social perceptions regarding cancer, disclosure and stigma are embedded historical and political contexts. For example, any relationship with German soldiers was considered stigmatized during and after the Second World War in Denmark (Svendsen 2006: 151). As a result, they were excluded as fathers from maps of kinship which prevented the transparency of family history in genetic counseling of cancer (Svendsen 2006: 145). In another historical instance, during the socialist era in Central and Eastern Europe cancer was equated with leprosy, and it was believed that it could transfer to another person through a handshake (Kozikowski 1998: 63). Hence, the depiction of cancer in cultural, historical and political contexts has invoked fear, awe and uncertainty throughout history. This lends itself to understanding cancer and its multifaceted impact on individuals, social groups and institutions through cross-cultural explanations of disease and illness.

Explanatory Model: Cultural Models of Illness

Cultural constructs of disease and illness direct the understanding of cancer. Various scholars have presented their viewpoints on disease and illness as intertwined mechanisms that are in constant co-existence. According to Kleinman, illness characterizes the lived experience of an individual and the perceptions and response of the family and larger social networks to that individual's symptoms. On the other hand, disease is a manifestation of pathological symptoms that a physician has been trained to treat (Kleinman 1998). Likewise, Brown (1998) suggests that any disease is an "observable and pathological abnormality" independent of cultural acknowledgement while "illness is the perception and experience of being sick".

On a similar note, Douglas proposes that the human body is a bounded system which encapsulates both physical and social states of existence. (Douglas in McGee and Warms 2004). Scheper-Hughes and Lock (1987) underline that the human body manifests as three forms: an individual body-self, a social body in relationship with its socio-cultural environment and a body politic governed by social and political control. For instance, chest pain might be a symptom of coronary artery disease as per the biomedical model. However, it may be a result of complex interlinked bio psychosocial processes such as cardiovascular factors (hypertension), psychological factors (panic), and environmental factors (loss of a family member or divorce) which coproduced the symptom or the disease (Kleinman 1998).

Hence, given the inherent interaction between the pathological manifestation of disease and the social components of illness, critical medical anthropology critiques the notion that biomedicine or western medicine is free from cultural influences (Brown 1998). In addition, many cultures have multiple alternative medical systems that can be broadly classified under naturalistic and personalistic ethno medical systems (Foster 1998). Naturalistic systems primarily

focus on the pathological causes of disease while personalistic systems view disease as a product of physical and social factors (Foster 1998). While a given medical system cannot be fully compartmentalized under either of these categories, these classifications help to recognize the role of illness narratives and parallel pathways of treatment in the case of certain diseases including cancer.

For instance, traditional healers in Atteridgeville, South Africa provide consultations on cancer-related health education and strategies for cancer prevention and were considered to be a key resource for collaborating with health care workers regarding efforts concerning cancer care and awareness (Steyn and Muller 2000). Similarly, Gyamenah's study presents the application of a personalistic model in native explanations of cancer in Ghana (2015). Menard's study among Haitian immigrant women highlighted the personalistic explanations for cervical cancer such as pollutants, canned food, spells divine retribution though Menard also cautions against the oversimplification of ethnomedical categories since it runs the risk of undermining traditional knowledge and practitioners, and the overlap in the use of traditional and western therapies (Menard 2008). Hence, these studies illustrate the overlap between the existence of human body as a mode of physical and social existence and the embodiment of cancer as a bio-social phenomenon.

Cancer, Gender and the Lived Experience

In addition to explanatory models of illness, studies have explored the relationship between cancer and stigma and their influence on gender, social roles and cultural validation within social groups. The scenarios related to non-disclosure of a cancer diagnosis create an interesting narrative with regard to parallel roles of power within a family unit. For instance, a

male member who is conventionally considered to be the “head of a household” might be held in high regard with regard to making major decisions concerning the household. However, the same individual might not be able to participate in health related decisions if he is diagnosed with cancer and has no knowledge or limited knowledge of his diagnosis and prognosis. In this regard, the term “agency” itself has shifting meanings and contexts within a given situation and the broader sociocultural dynamic of a family unit. For instance, women in a family unit might be held accountable for lending emotional and moral support and provide nursing services as caregivers. However, they may be expected to fulfill these obligations in addition to working outside the domestic sphere (Rudrappa 2004). On the other hand, men are expected to provide financial support including costs associated with the treatment (Bossart 2003). Therefore, women may face more disparity in decision-making processes than men, given their primary positioning as caregivers as per conventional gender norms.

In addition, cancer as an illness has a deep impact on the perception of social roles, sexuality and normalcy among individuals diagnosed with cancer. Martinez et. al outline the relationship between cervical cancer and gendered perceptions regarding patriarchy, sexuality and morality among Latina immigrants from Mexico and El Salvador, which can be traced to the influence of Spanish colonialism in Mexico and Central America (Martinez et. al 1997). Since high regard is placed on virginity and fidelity among women (Hondagneu-Sotelo 1994; LeVine 1993; Horowitz 1983 in Martinez et. al 1997), any behavior that can be construed as sexually aggressive or promiscuous is considered beyond the boundaries of social order and is associated with consequences for women’s health (Martinez et. al 1997). These beliefs significantly influenced the perceptions of the Latina immigrants regarding cervical cancer causing them to associate cervical cancer as retribution for bad behavior (Martinez et. al 1997) and as a means of

stigmatizing other women (Gregg 2003). In addition, the perception of cervical cancer as a “dirty disease” due to the associated sexual taboos adds to the layer of stigma related to cancer (Chavez 2005; Treloar et. al 2013). Similarly, the effects of lung cancer cause patients to indulge in feelings of anger, guilt and blame towards themselves due to the stigma and a sense of personal responsibility attached with smoking (Chapple 2004).

Manderson (1999) notes that the post-surgical “cured” body still might be viewed as out of control since patients have to cope with scar tissue and physical disability related to surgical interventions on a daily basis. Hence, aspects of the social body need to be “reconfigured” given the process of negotiation centered on agency, gender and mental capacity which involves coping, self-reflection, depression, fear and sadness. Changes in normal bodily functions due to illness can make a person dependent on care. Therefore, the process of reclaiming normalcy often entails asserting one’s social identity. However, the loss of bodily parts associated with gender and sexual identity in particular challenge the socially constructed identity of gender. For example, men who underwent prostate surgery due to cancer reported dealing with their condition with stereotypical masculine qualities of self-control, rational thought and mental resilience (Gannon et. al 2010). Their health condition presented them with the dilemma of walking a fine and difficult line between enacting the traditional traits of masculinity and coping with the weakness and disability that comes with cancer (Stansbury et. al 2001). In other cases, the ability to be a “provider” or an earning member was given precedence over feelings of sexual normalcy in terms of self-worth (Manderson 1999).

Likewise, cultural expectations of mothering, of women as nurturers can place undue stress on women who are undergoing or have undergone treatment for cancer causing them to feel inadequate as caregivers (Bell and Ristovski-Slijepcevic 2011). Women who undergo

mastectomy may try to reconnect to themselves as sexual and gendered beings. Likewise, the possibility of castration due to testicular cancer may lend itself to experiencing feelings of loss pertaining to sexual and gender identity among men especially considering the increased promotion of gyms and sexual health in popular culture (Manderson 1999). Sedgwick (1991) and Lorde (1997) lay out the relationship between illness and its associated contexts in relation to how gender is performed and expressed in relation to cancer. In reaction to her diagnosis of breast cancer - “Shit, now I guess I really must be a woman” (in Lochlann 2007), Sedgwick emphasized that it was the cancer that was the site of trauma, and not the breast, since the existence of the breast preceded the cancer. Through this statement, Sedgwick emphasized the separation of her self and her identity from cancer even though she argues that cancer is perceived in the patient through notions of gender normativity and norms. Similarly, Lorde criticized “breast cancer culture,” which is predominantly concerned with women’s disguise of cancer through the use of makeup, wigs, and prostheses (Lorde in Lochlann 2007). For Lorde, the pressure and expectation of keeping up appearances negated women’s experiences of cancer. It prevented them from reaching a state of complete acceptance with regard to their health condition, and it compounded the stigma of cancer by making them feel less “womanly” (Lorde in Lochlann 2007). Both Sedgwick and Lorde’s analysis underline the argument that it is the site of cancer in the physical body that tends to be the focal point of intervention in the biomedical imaginary and popular culture which may overlook the personal and social impact of cancer on an individual’s life.

In addition, the various side effects of cancer therapy such as fatigue, muscle pain, hair loss, fear of recurrence, anxiety, depression (Horlick-Jones 2011) stigmatize the state of being diagnosed with cancer. Apart from repercussions for physical and mental health, a cancer

diagnosis has implications for rehabilitative and functional concerns. Stewart et al (2001) estimate that 6 million individuals experience disparate treatment due to their medical histories in the United States. Most employers tend to associate the diagnosis of cancer with short-term survival, low productivity and contagion. Thus, discriminatory treatments may include loss of benefits, dismissal from employment, lack of promotion, unwanted transfers, hostility at work place and non-job performance related random mandatory medical examinations. In addition, patients may experience refusal from insurance companies, higher premiums and the denial of disability insurance (Stewart et. al 2001). Hence, disease is not divorced from the category of ascribed social identities and roles. It acquires multiple meanings for the physical and the social body through who inhabits it and who is looking at it.

Fatalism, Agency and Faith as Coping Strategies for Cancer

With regard to the existing literature, and the severe physical and social impact of a cancer illness, studies have explored the role of fatalism, moral reasoning, religion and faith as coping strategies in dealing with cancer. Fatalism is defined as the “lack of personal power or control over destiny,” as human beings are powerless to change certain predetermined events (Drew 2011). Correspondingly, the term “cancer fatalism” alludes to the belief that death is inevitable in the presence of cancer. The notion of cancer fatalism has been employed to understand the lack of preventive measures such as cancer screenings, failure to follow through abnormal results or refusing treatment all together (Drew 2011).

Fatalistic beliefs about cancer are present in various cultures. Aboriginal Australian groups, for instance, may consider cancer to be a form of punishment or ‘payback’ (Treloar et. al 2013). Similarly, notions of receiving ‘karmic’ punishment in the form of contracting a particular

disease, especially a potentially terminal illness such as cancer, are also prevalent within factions of Indian society. Cancer was considered to be an affliction that patients “brought upon themselves” in the late 19th and early 20th centuries in Europe and the United States (Kozikowski 2005). In addition, structural inequalities perpetuate fatalistic beliefs about cancer and contribute towards the prevalence of non-disclosure of cancer. Hence, structural inequalities are masked under notions of fatalism to serve as explanatory models of cancer in certain cases.

Even though the terms fatalism and destiny are used interchangeably, Florez et. al (2009) distinguish between the two through the narratives of breast cancer in a study among Latina women in the Dominican Republic. In the study, participants identified with the concept of destiny regarding their perception of fate and breast cancer but did not consider it to be a process over which they had no control. Instead, they considered destiny to be a combination of genetic history and personal agency. They believed that a person might be “destined” to get cancer because of their genetic makeup or family history of disease, but that the outcome can be mediated via early diagnosis, treatment and personal actions.

Thus, the idea of destiny corresponded with probability in this particular case, which could be shaped through personal efforts unless factors beyond an individual’s control such as a fatal outcome due to lack of treatment or a timely diagnosis, and/or low socio economic resources. Hence, the study’s findings show that the traditional conceptualization of “fate” or “cancer fatalism” do not apply in a singular fashion (Florez et. al 2009). The study presented participants as assertive and proactive actors regarding choices related to health outcomes and assigning meaning to health related experiences. This illustrates the need for expanding cultural knowledge regarding existing ideas about social factors that contribute towards the reasoning of cancer. The participants in the study did not associate feelings of helplessness with the sense of

finality that usually accompanies constructs of fatalism. Instead, the belief in destiny enabled participants to actively participate in screening while reconciling with the possibility that there was a high likelihood of developing cancer given the factors affecting their health.

In addition, studies have shown the impact of cultural conceptualizations of faith and religion on imparting meaning to cancer and as a means of coping with cancer (Ahmadi et. al 2018). A study among American Indian and Alaskan Native women showed that a sample of the participants dealt with feelings of depression by indulging in traditional practices of faith such as burning sage, offering prayers and attending church (Burnette et. al 2019). Similarly, religious concepts and practices have played an important role in Indian culture considering that traditionally, India has been home to the development and sustenance of various civilizations, ethnicities and diverse socio-cultural practices. Ayurveda, one of the traditional medical systems in India is believed to have its foundation in ancient Indian Vedic texts. According to Chattopadhyay (2007), medical knowledge was often intertwined with a divine source or entity in ancient India. Therefore, the practice of medicine often converged with religious or spiritual activities as shown in historical records where Buddha frequently directed his disciples to care for the sick. King Ashoka who later converted to Buddhism created public facilities for the treatment of people. Similarly, Islamic traditions have had a long and continuous history of healing in India which included partnership between *vaid*s and *hakims*, which are respective connotations for traditional Hindu and Muslim practitioners (Alavi 2008). However, there came to be an increasing emphasis on the inception of disease as a singular and isolated pathological process. For instance, the birth of the clinic was a secular process where the notion of sacredness was removed and replaced with a domain that was meant to be non-religious (1979). Hence, non-religious oriented treatments took precedence over therapy which was inlaid with supernatural or

divine elements. In addition, medical care in India gradually transformed into a legal monopoly under physicians, which essentially shifted the act of healing from religious domain, and led to the centralized control of private behavior and professional medical authority (Feierman 1979).

Nonetheless, healing traditions continue to thrive in conjunction with religious and faith oriented practices given the historical intersections between religion and health. Immigrant communities often pursue socio-religious practices as part of preserving their cultural identity and as a strategic means of imbibing cultural values in future generations (Rudrappa 2004). In this regard, religious and spiritual activities also serve as a source of creating and increasing social support networks and promoting public health interventions among immigrant communities (Islam et al. 2014).

Section II: Perspectives on Cancer Disclosure

The “disclosure of cancer” in contemporary research refers to informing patients about their diagnosis, poor prognosis or impending death from cancer (Markovic et. al 2004). Following this, the patient is expected to make a decision regarding the course of treatment, its side-effects and outcomes given his/her assumed autonomy in the decision making process. However, cancer disclosure practices differ globally ranging from complete disclosure to partial disclosure to non-disclosure (Markovic 2004). Feelings of immense uncertainty, fear and denial often accompany a diagnosis of cancer in various cultures. Hence, in some instances is considered “cruel and legalistic” to disclose a potentially terminal illness in a frank manner (Gregg 2003). Early research regarding patient-physician communication examined physicians’ attitudes towards disclosure of cancer during the 1950s and 1960s. Studies indicate that even oncologists were reluctant about disclosing a diagnosis of cancer and were highly apprehensive

and unwilling to discuss the prognosis of cancer (Gordon and Daugherty 2003). Majority of the physicians that were surveyed from the earliest of studies shared that the only reason to disclose a diagnosis of cancer with patients was if that was the only alternative left to have them comply with evaluative or therapeutic intervention. The primary motivation was to prevent the patient from interpreting a cancer diagnosis in certain terms implying that it would lead to a painful death since the prognosis itself was assumed to be fatal just by virtue of being diagnosed with cancer.

However, advancement in screening technology such as the advent of CT scans and minimally invasive biopsies, and the reduction in anxiety regarding perception of cancer as a fatal disease in addition to the need for improving communication with patients for compliance with therapy, normalized the full disclosure of cancer in medical practice by the 1970s (Schaepe 2011). In addition, this prior approach that discouraged full disclosure has faced severe criticism under accusations of medical paternalism, which is defined as acting in an individual's interest without taking his/her will into consideration (Sullivan 2016). Hence, biomedical approaches and practices regarding cancer communication have undergone a gradual transition from silence regarding cancer to focusing on survival. In spite of these developments, physicians may still often indulge in genteel and vague communication with the patients. For instance, they may refrain from using the word "cancer" and instead use terms such as "growth", "lump", "abnormal cells", or "precancerous condition" during initial consultations even when they are obligated to fully disclose a cancer diagnosis under the obligation of informed consent. Similarly, indirect references to cancer form also part of consultations that involve transitioning from therapeutic to palliative care (Schaepe 2011). Studies in Sweden, Taiwan and Iran have shown that family members have withheld the diagnosis of cancer from patients in order to protect them from

feelings of desolation and despair. Non-disclosure rates are particularly high in Asian countries considering the prevalence of a family oriented model of decision-making (Chittem et. al 2013).

While the decision to not disclose a cancer diagnosis has been perceived to be an act of altruism (Gregg 2003; Good et. al 1990), there are opposing arguments to this viewpoint, especially the implications of such (non) disclosure practices on the patient's agency.

DiGiacomo describes the choice of family members as being a "barrier" between the patient and the physician as an act that forces "a conspiracy of silence" that marginalizes the patient while he/she is undergoing chemotherapy or radiotherapy (DiGiacomo 1999). DiGiacomo presents the following common assumptions behind non-disclosure of a cancer diagnosis. According to her, patients either do not want to know their diagnosis or family members presume that patients become aware of their diagnosis only when they are told explicitly. Additionally, family members may feel that there is no need to share the diagnosis with the patients since they already know or sense that they have cancer. Also, family members might be concerned that patients could experience distress or depression and could potentially commit suicide if they came to know about their diagnosis. Furthermore, family members likely assume that they have a better sense of whether the patient should be told the diagnosis than the patient or the physician. In addition, family members think that the patients tend to willingly accept an alternative diagnosis such as having an "inflammation" or a "cyst" and usually may not expect more information from their physicians. Thus, patients may accept chemotherapy or radiotherapy treatment while demanding the reassurance that they do not have cancer. Lastly, denial can be instrumental in adapting well to the illness and only public health education about cancer can effectively tackle cancer related silence and denial (DiGiacomo 1999).

DiGiacomo (1999) asserts that the silence around cancer related conversations establishes a social code that gives away the reality of the diagnosis to the patient. Thus, it is highly probable that cancer patients become aware of their diagnosis by a certain stage of the treatment. He further opines that the issue at hand is about the acknowledgement of a cancer diagnosis in social space and not about lack of knowledge with regard to having cancer if the patients are willing to accept an alternative or false diagnosis regarding their health condition since a cancer diagnosis is usually viewed as comparable to a death sentence. She vehemently critiques this practice by implying that the non-disclosure of cancer becomes a “social fact” that is intended to “tranquilize” the patient and not comfort him/her eventually leading to a kind of social death that family members are trying to prevent. DiGiacomo (1999) frames the willingness of physicians who chose to side with family members regarding non-disclosure as “benevolent paternalism” and posits that younger physicians tend to favor disclosure over non-disclosure of cancer with changing attitudes regarding the issue.

While DiGiacomo makes some valid points in her critique of non-disclosure of cancer, she does not adequately consider the diverse cultural contexts in which disease and illness mechanisms operate. In addition, social and economic inequities, lack of access to healthcare and insufficient knowledge are significant factors which influence health outcomes (Drew 2011). As Kozikowski notes, poor health infrastructure, lack of access to physicians, shortage of medications, poor hospital conditions coupled with the perceived social disgrace of having cancer frequently caused patients to lose trust in biomedicine in eastern and central Europe. The notion of cancer as a contagious disease formed its perception as a social problem, which did not fit well with the idealized image of a healthy nation (Kozikowski 1998). Hence, cancer was largely ignored which further strengthened the norm of secrecy. This shows the implications of

how the understanding of disease is the sum of multiple cultural factors that go beyond the context of genes and biology.

Another aspect of disclosure relates to contemporary clinical ethics. From a biomedical ethical perspective and the obligation under HIPAA (Health Insurance Portability and Accountability Act of 1996), a patient has the right to access his/her complete medical information which calls for a direct communication between the provider and the patient. Thus, the right to information is at risk if the patient is not granted access to any information regarding his/her health status. However, the patient's family might be an important source of moral, emotional or financial support for the patient especially in cultures that adhere to familial models of decision making which places immense weight on their perspective in a situation.

In addition, a cancer diagnosis can be distressing and eventful even for family members in the face of emotional and financial uncertainty regarding a cancer prognosis or the sheer amount of time, emotional energy and financial resources required to cope with the illness. Hence, family members cannot be excluded from the cancer disclosure, given cultural models of decision making and the implications of the diagnosis for the family which includes anxiety and depression (Edwards and Clarke 2004). In light of this aspect, Lindquist argues that the term "health seeking units" (2002) is perhaps more adequate than "patients," if the patient is not the sole or primary decision maker in a particular social context. Therefore, the experience of illness can have a collective and compounding impact in varying degrees on a number of individuals even though the disease might inhabit the body of just one individual. Therefore, it is easier to assume in ideology than practice that the patient has the right to know under all circumstances when there are immediate and far reaching consequences for everyone involved illustrating the collective effect of illness on the entire family unit.

The literature on cancer disclosure practices provides the intersubjective relationship between collective models of decision making, familial altruism and the associated cultural context of benevolence and individual rights. With regard to varying opinions on disclosing a cancer diagnosis to the patient (Gregg 2003; Good et. al 1990; DiGiacomo 1999), interestingly, there are also cases where patients have expressed their preference for not knowing the details of their health information. For example, Akabayashi et. al (1999) present a case study in which a 62 year old Japanese woman diagnosed with advanced gall bladder cancer expressed the desire to not know about her diagnosis. The woman was admitted due to suffering from fever and severe back pain. A series of tests revealed that the cancer had metastasized to the liver and the back. She was not considered to be an ideal candidate for surgery or chemotherapy since her expected survival was less than three months. Palliative treatment through pain medications was considered to be the recommended therapeutic approach in her case (Akabayashi et. al 1999).

This example illustrates various intricacies associated with the disclosure of cancer. On one hand, it depicts the self-determination and agency of the patient while on the other, it illustrates the role of the family and the physician as gatekeepers in a different light considering that the family members and the physician were aiding the patient in not knowing about her condition as per her preferences. The unwritten moral and ethical code in this case was being applied to support the wishes of the patient. The complexity of this case does not neatly fit within the paradigm of bioethics and the way in which it conceptualizes the principle of autonomy. As evident in this case, an individual may autonomously decide *not* to know the revelation of a particular disease perhaps because the lack of awareness regarding a confirmed diagnosis can be a tacit means of coping with the lived reality of an illness within particular social parameters. This elucidates a different ethical question which is whether it is ethical to share a diagnosis with

a patient who does not want to know. This case illustrates that the sociocultural implications of “truth telling” have diverse implications for individuals, families, ethics and biomedical practice. In addition, the perplexity of cancer disclosure practices and bioethics further mystifies the issue of disclosing a cancer diagnosis to individuals with intellectual disabilities (Tuffrey-Wijne 2010) considering their vulnerability in dealing with the information.

According to Collier and Lake (2005), the notion of “regime of living” refers to an assortment of elements regularized, institutional and technical elements concerning ethical situations where the question of “how to live” is placed at stake. The word “regime” alludes to “a manner, method, system, rule or government” including the principles of rational thinking, value systems and practices that are consistent. In addition, these principles function on the basis of what is deemed as good and ethical on the individual and the collective level (Collier and Lakoff 2005). Under this paradigm, the biomedical system focuses on the diseased individual and not the social organization of relationships since there was no scientific rationale for pursuing the social life (Feierman 1979) or lived experience of the individual let alone the social web of relations in which the lived experience is embedded. Hence, the socio cultural context of a population and the lived experiences of the individuals deserve preeminence over the uniform application of bioethics as they are conventionally understood in the biomedical realm. A rigid and uniform approach resulting from a normative mode of thinking tends to be devoid of the socially complex nuances that encompass the fragility and diversity of human experience, which ultimately leads to the expectation of constitutional subjects (Collier and Lakeoff 2005).

Familial Altruism, Cancer and Therapy Management

The concept of therapy management, a term coined by Arkininstall and Janzen in “The Quest for Therapy in Lower Zaire” in 1978, refers to a group of individuals who might be kith or kin who gather information, lend moral support, make decisions and communicate the details of the therapeutic consultation with the patient (Janzen 1987). The two primary features of therapy management are 1) A set of actions that devise a diagnosis and select and assess treatments for the patient 2) The group of individuals who facilitate these actions and act as mediators and advocates between the patient and medical staff (Genest in Janzen 1987).

Therapy management has been mentioned in Central African research innumerable times. The term “therapy management” describes a practice where an individual who is legally responsible for the patient is also in charge of medical consultation and referral during the process of diagnosis (Babutidi in Janzen 1978; 1987) although the Kongo people [affiliated with the kingdom of Kongo and now part of present day Angola (Fromont 2018)] did not formally grant decision making rights to a health professional. Apart from the Kongo, “escorts” in urban Zambia were responsible for providing social support to the patient during times of illness though there is no mention of their role in evaluating medical information or making decisions for the patient (Boswell in Janzen 1987). The terms “lay referral” and the “hierarchy of resort” are also remotely associated with therapy management while the term itself came to be as a way to explain social and environmental factors that explain decision making mechanisms (Janzen 1987).

The concept of therapy management imbibes social and cognitive aspects considering that the social relationships among all concerned individuals and how they influence and mold clinical knowledge and illness related experiences. Hence, understanding the process of therapy

management involves a cumulative understanding of social patterns and interpersonal exchange within a group. Although the study of social support networks has also provided insights into group dynamics, they may not always specifically account for the implications of agreement and disagreement regarding therapy in a group or the ways in which individuals apply knowledge pertaining to diagnosis and treatment. Janzen distinguishes between therapy management groups and social support networks by highlighting that therapy management groups specifically focus on decisions regarding therapy and illness management (1987).

Hence, the study and application of therapy management groups in medical anthropology can be used to better understand patient behavior in contrast to a unidirectional viewpoint that considers the individual as the sole actor in the sick role, and as the only decision maker instead of considering differing therapeutic perspectives within a group (Janzen 1987). In addition, therapy management posits the illness experience within various interconnected layers of social context that include the individual, the clinic, the ritual of healing and the socio-political system on a larger scale. In this regard, the concept of therapy management highlights the social embeddedness of knowledge and further strengthens the case for studying plural medical systems. In addition, it extends a more nuanced approach towards studying underlying social dynamics among patients that are considered to be “non-compliant” or “failures” by not limiting such behaviors as the fault of an individual or a product of different cultural systems but also accounting for the social actors that exercise control and the different ways in which they do so within a given social unit (Janzen 1987). The emergence of therapy management has facilitated the creation of specialized communities that provide care and treatment to their community members. However, this aspect differs within the Asian Indian context to a certain degree given

the existence of a collective model of decision making which precedes and espouses the practice of therapy management among Asian Indian communities.

Therapy Management Groups and Social Dynamics

As mentioned earlier, family members generally play a central role in managing illness in therapy management groups among the various stakeholders which include the patient, healthcare professionals and friends and family members (Bossart 2003). However, Bossart argues that the emphasis placed on the significance of social networks has been overestimated in the literature in her discussion on popular assumptions regarding therapy management groups (2003). Bossart emphasizes that social networks play an important but limited role in responding to illness, since there are specific social equations in place that determine the ways in which assistance is granted to the patient. Household members tend to be the primary source of assistance to the patient, while on the other hand the support of extended family and non-family members is usually limited to emotional and moral support. Thus, household members yield greater control on important decisions in comparison to extended family and friends.

Also, socioeconomic circumstances limit the support and illness management offered by household units. Family members themselves might feel emotionally and mentally exhausted due to the needs of the patient or other members in the social network. Patients may not receive adequate support in case of chronic, rare or stigmatized illnesses. Hence, a significant number of individuals tend to be alone while coping with their illness instead of having their illness managed by a social network (Bossart 2003). While Bossart presents an important critique of therapy management in relation to the emotional and financial cost of managing illness, the step of withdrawing from management of illness is also a major decision that has significant

emotional, financial and therapeutic consequences for the patient which affects the process and experience of illness.

Therapy Management Groups and Individual Decision making

Therapy management groups are often inherently diverse in their composition given the presence of various stakeholders that may or may not belong to similar educational and financial backgrounds. This diversity also lends itself to the presence of different thought processes and therapeutic viewpoints which may overlap or diverge within that group. Thus, therapy management groups do not accord ultimate professional authority to any one practitioner or physician given the plurality of therapeutic opinions and approaches (Feierman 1979).

In addition, major decisions regarding treatment often lie within the hands of the bonafide members in therapy management groups irrespective of whether they possess the professional knowledge and training to decide on the matter at hand (Feierman 1979). Furthermore, Lindquist emphasizes that individuals within a therapy management unit are not passive receivers of medical and institutional authority who accept any one system of knowledge. Instead, they proactively select elements of therapeutic knowledge that they consider beneficial to the patient while participating in a social space where power is contested and framed within specific social parameters (Lindquist 2002). For instance, Russian participants shared cases where a diagnosis of cancer was conveyed to close relatives which usually included the spouse and children but not the patients. Thus, the patient is unable to exercise agency with regard to devising strategies for his/her treatment (Lindquist 2002; Dohan and Levintova 2007).

Physicians, nurses and relatives of the patient often form a “powerful clinician-kin hybrid” as part of therapy management groups (Livingston 2009). During her research among

cancer patients in Botswana, Livingston observed that the therapy management groups in the clinical setting would often conceal the status of being terminally ill even if the patients were aware of their cancer diagnosis. Livingston reports a particular instance where a patient's family, nurses and doctors decided not to let the patient know that his cancer had advanced to the terminal phase. They perceived their decision to be an act of compassion since they were concerned that the patient might experience increased stress, or even consider suicide and thus might even lose the remaining days of his life. Livingston also recounted the narratives of nurses in the oncology ward who expressed experiencing extreme distress over witnessing the death of patients since patients "became like their family" (Livingston 2009). These narratives indicate how medical professionals participate in therapy management groups not just by virtue of professional training but also by forming symbolic bonds of attachment that are not based on kinship ties unlike family members. This dynamic also presents the possibility of lines blurring between clinical decorum and personal space in an otherwise sterile and impenetrable institutional setting which stands for detachment, objectivity and authoritative knowledge.

These narratives show that clinical settings are not just sites of medical knowledge that practice medicine in isolation with the social environment. Instead, they influence and are influenced by the sociocultural dynamics of how illness affects both suffering and healing and hence are open grounds for initiating a medical practice that provides therapy while accounting for the lived experience of patients and families. Although Livingston presents a vivid portrait of the suffering that cancer patients undergo, she also highlights the challenges that the medical staff and families of patients face in "managing" the illness of the patients. Livingston's findings reify the experience of illness as a narrative that is lived and told by various actors who are affected by it. This posits the experience of illness as a mechanism that operates collectively

leading to the creation of cohesive groups that not only want to manage the therapeutic process and palliative suffering for the patient but in doing so also want to manage their own emotional reaction to a particular illness and the prospect of mortality brought upon by that illness.

Moreover, the degree of exercising control over suffering, therapy and decision making further intensifies in a given situation if the concerned illness is chronic, insufferable and terminal.

Bioethics, Cancer and the Political Economy of Hope

Although family members play a critical role as caregivers to patients in oncological care and therapy management, their participation in decision making can pose challenges for the agency of the patients. Given this predicament, Kleinman (in Turner 2009, 25) and Good et. al (1990) have critiqued the western notion of bioethics as a concept that does not account for complex social realities of illness. Additionally, Muller argues that the inception of western bioethics is embedded in a socio-historical context that is specific to certain events. For example, while scientific and technological innovations in medicine were instrumental in the creation of the field of bioethics, defining historical events such as the recruitment of patients for chronic dialysis in Washington, Seattle in 1962; heart transplantation in South Africa in 1969; the Tuskegee and Willowbrook experiments in 1972 played a key role in the inception and definition of bioethics. The origins of bioethics are believed to primarily align with Anglo American philosophy that emphasizes individual rights, independence and privacy (Muller 1994).

Thus, bioethics champions a thought process which is rooted in rationalism, objectivity and prescriptive behavior that supports normative thinking based on how decisions should be made and not how they are made in conflicting situations (Muller 1994). The principle of autonomy is highly significant out of the four primary principles that govern the model of

bioethics. It stresses that individuals who are in a position to decide for themselves should be able to do without any obligation and with due respect towards their decisions. The principle of autonomy has also contributed hugely towards the theoretical development of patient-physician behavior, rights of the patient and moral responsibility of the physician towards the patient. The principle of beneficence focuses on providing benefits to the patient, minimizing risk and acting in the best interest of the patient. The principle of non-maleficence refers to the avoidance of a harmful act and the principle of justice encourages a fair distribution of benefits and risks in accordance with the criteria of allocating minimal and costly resources (Muller 1994).

However, the principle of autonomy has been critiqued for not supporting “communitarian ethics” (Muller 1994) since it does not acknowledge the obligations that an individual might have towards the members of his/her community. Also, it has been criticized for being short sighted about the real nature of a physician-patient relationship where social relations command more value than an individual patient while dealing with a bioethical dilemma. The notion of autonomy does not account for the totality of the lived human experience by not taking into considerations the unique and collective factors that shape the composite experience of illness for an individual.

According to Hoeyer, “Bioethics lives a double life: it is both organizational practice and moral dilemma, both politics and morality” (Hoeyer 2006). Lopez (2004) identifies two broader applications of bioethics – one which views bioethics as a discourse and as an institutionalized practice resulting from a wider political analysis of historical, political, cultural and economic conditions while the other emerging from an ethnographic focus on the ways in which social actors inculcate and practice morality and ethics (in Hoeyer 2006). According to Hoeyer (2006), the dialogue on bioethics is either presented as a discourse on power or on moral dilemma but

rarely does it imbibe both aspects in ethnographic research. This is by virtue of the fact that ethics are essentially an execution of power but power that presents itself as morally significant although morality can vary based on social dynamics. Correspondingly, Appadurai (1986) argues that policies on ethics shape the social life of moral issues leading to the embodiment of certain moral positions in institutional structures while certain other issues might be excluded from consideration (in Hoeyer 2006). Marshall (1992) further critiques the model of bioethics as a product of reductionist and utilitarian approach to problem solving which distances the moral discourse from complex human social interactions where moral dilemmas are created, contested and negotiated.

Additionally, Good et. al (1990) outline various levels of the international biomedical culture that co function to produce the “political economy of hope”. They assert that societal, traditional and medical norms, and the history of medicine influence the culture and practice of biomedicine at the regional, national and international level which is evident through the interaction between physicians, patients and families. In addition, forms of medical disclosure, physician-patient interactions and dominant oncological specialties influence and are influenced by types of oncological treatment and biomedical technology. Lastly, the political economy of oncological research and practice aligns itself with the local interpretation of hope in a culture or community. In this regard, Good et. al (1990) present three key aspects of the oncological culture and practice – 1) the ways in which physicians manage conversations regarding disclosure, prognosis and treatment 2) the ways in which physicians sustain hope among themselves, patients and family members 3) the ways in which physicians cope with challenges related to clinical practice and the faith placed in the effectiveness of science and technology to counter the limits of hope (1990).

In addition, funding initiatives with regard to cancer thrive on the phenomenon of hope and the possibility of cancer being curable. Therefore, institutional entities affiliated with oncological research and treatment are linked with the “political economy of hope” considering the promotion of anti-cancer therapies and search for healing among patients and families through the use of various treatments (Good et. al 1990). For instance, American Cancer Society and the National Cancer Institute have enthusiastically promoted the “message of hope” and the “war on cancer” which highlights the connection between social movements and attitudes regarding types of disclosure, values such as frankness or secrecy associated with disclosure, types of treatments and institutional investments. Thus, the concept of ‘political economy of hope’ highlights how individual aspirations embroil with larger socio-cultural, political and economic processes where a variety of stakeholders such as scientists, clinicians, government and biotechnologies have diverse interests in the practical application of research (Good et. al 1990).

It is important to consider that a diagnosis can carry meaning beyond the individual corporal context. It includes social meanings pertaining to what the diagnosis means for the patient and his/her family as well as the social relationship between the individual and the family, and the patient and the provider. For instance, a family may reach closure regarding the end of a “living” relationship and the loss of social roles fulfilled by the individual during the prognosis concerning a terminal illness. However, the physician may feel obligated to continue the therapeutic relationship with the patient that was established as part of the Hippocratic Oath. However, the aforementioned situation can also be reversed in a situation where the family may not feel ready to accept the reality of a poor prognosis which changes the meaning and experience of the illness for the family.

Although American oncology and biotechnology enjoy a coveted status in the domain of international medicine, the American practices of cancer disclosure differ significantly from certain non-American clinical settings considering the cross-cultural contexts of cancer disclosure. These findings show that the domain of ethics is not absolute but transitional and evolving based on the specific sociocultural context in a given time period. In addition, while the lack of a competent health infrastructure is one of the factors that has contributed to the practice of non-disclosure of cancer in certain places (Kozikowski 2005), the availability of complex and proficient cancer treatments do not ensure the absence of full disclosure of a cancer diagnosis.

With regard to cultural differences in biomedical practices concerning disclosure, Italy and Japan provide medical facilities with advanced biotechnology and treatment at various popular oncology clinics, yet these cultures dissent with the American oncological ethic of full cancer disclosure given the underlying assumption that doing so is not only callous but would lead to “social death” (Good et. al 1990). The concept of “social death” corresponds with the idea that a patient may be biologically and clinically alive but is considered to be socially dead (Timmermans and Sudnow 1998) or when an individual considers himself or herself to be “as good as dead” due to a fatal illness, old age or loss of personhood such as in the case of dementia (Sweeting and Gilhooly 1997). Thus, it is not merely technological and therapeutic innovations that shape clinical practice but also popular and medical cultures. However, the increased collaboration among health practitioners and clinics on the domestic and international scale seemingly challenge cultural attitudes towards disclosure and patient-physician relationships although local sensibilities regarding disclosure also significantly influence the response towards diagnosis and treatment of cancer.

While there is considerable literature on various aspects of communication between patients and health care providers, the ethical issues regarding disclosure of health related information are yet to be explored. According to Good (1991), the connection between disclosure and treatment of cancer, and cultural perceptions of the mind and body affect individual and professional response to the diagnosis of cancer in the United States. She observes that oncologists in the United States often view frankness and full disclosure of cancer as an essential step in creating partnership with the patient as well as a therapeutic strategy for enabling patients to manage their illness in a more responsible manner.

The discontent with the present bioethics model has led to developing a reflexive approach in framing the conversation on bioethics. This implies that one needs to view bioethics in a cultural context that accounts for the social and cultural realities in lived experiences of illness. Hence, to look at bioethics and the notion of autonomy as infallible is problematic. Therefore, it is necessary to address the issues of interdependence in family units and the community at large in ethics research. Callahan (2002) addresses the conundrum of bioethics as “moral obsession” where the social issues of political economy, culture and tradition take a backseat even though socio cultural and historical determinants embed medical practice. However, the development of ethical reasoning which is based on social context and is situated in moral conduct and not moral theory in medical practice can transform clinical care into a more conscious and proactive model of healthcare.

As Marshall (1992) notes, conflict resolution is an important aspect of ethics consultations, it is precisely within this context that a transformation of the patient-physician relationship can occur. An ethics consultation necessitates discussion about the caring dimensions of healing rather than the biomedical facts about disease. The application of a

process of moral reasoning in clinical decision making facilitates a dialogue that promotes self-awareness and sensitivity to the inherent vulnerability of patients, families, and caretakers. Participation in an ethics consultation decreases the sense of powerlessness that so often accompanies an experience of illness. Together, these aspects of clinical ethics consultation have transformative potential in the treatment and management of illness and disease.

Overall, there has been a gradual shift regarding the image and discourse on cancer (Weiss 1997). The dialogue on cancer has imbibed a seemingly positive approach in its articulation of cancer. Descriptions such as “survivors” (Mullan 1985), “victors” (Pepper 1984), “exceptional patients” (Siegal 1987) have found a place in the domain of cancer communication (Weiss 1997). The issue with such linguistic juxtapositions is that they embody the antonym, the opposite in their conceptual framework. The idea of a “motivated” patient is defined as an individual who “complies” with all protocols regarding treatment and actively engages in his or her own self-care. This includes staying positive and adhering to the framework of recommended treatment irrespective of feelings of frustration or pain that a patient may experience during the period of treatment (Becker and Kaufman 2009). These frame of references place the burden of agency on the patient even though survival in cancer or any terminal illness for that matter is not always a choice. The rhetoric of “battling” cancer imparts a military like disposition to the experience of illness where patients are compliant fighters as per biomedical expectations.

Thus, the discourse on hope has invoked the debate on the meaning and efficacy of hope in clinical practice on the ground while facilitating the development of oncological subspecialties (Good et. al 1990) in part due to technological development but also due to ideological framework. Both American oncological practice and popular culture are deeply embedded in the discourse on hope in ideology and practice. The emphasis on will which is triggered by hope is

intricately tied with the ability to affect the trajectory of disease in the body. Hence, the perceptions regarding the relationship between the mind and the body also subsequently impact beliefs about disclosure.

Bioethics and Cancer: Ethical implications of Collective Decision Making

As mentioned earlier, even though the familial model operates within an altruistic framework of protecting the patients from a diagnosis of cancer or “bad news”, it raises questions regarding the short term and long term ethical implications of collective decision making. In the event that a patient was initially unaware of his/her diagnosis, there is a possibility that a family member may share complete details about the diagnosis with the patient or he/she may find out as the disease advances. This may lead to either the patient accepting his/her illness or may feel betrayed because he/she mistook the symptoms for another diagnosis. The patient may feel that he/she might distrust family members regarding future therapeutic or family decisions once the diagnosis comes to light. In addition, the patient may feel a sense of “stolen agency” thinking that he/she could have done reasonable action to alleviate the illness “when there was time.”

Also, they may feel neglected and think that they could have sought social support and appropriate guidance through other channels such as online support groups only if they had awareness regarding what was going on with them. Patients may also feel deprived from making end of life decisions regarding critical issues such as last rites, important personal belongings and legal inheritance in cases of terminal illness or cancers that have advanced to the terminal stage. In addition, this has implications for other family members such as minor children who may never know about a parent’s diagnosis or may feel that they did not receive enough time to come

to terms with the illness in case it was terminal. They may also feel that they never had the opportunity to express their feelings to the parent or make full use of the available time to bond with the parent when he/she was alive. At the least, they may feel excluded or isolated for not being part of the conversation even if the parent survived the cancer. This may also normalize non-disclosure of cancer or any illness deemed critical or uncomfortable by setting a precedent for them to act in a similar manner if they are in a situation akin to the present scenario.

In other cases, families and health care professionals may conceal a terminal prognosis of cancer even if the patient is aware of the diagnosis. Pain is a significant, and yet an unspoken aspect of dealing with cancer as per cultural norms in Botswana. The families of cancer patients in Botswana usually articulate the patient's pain, instead of the patients doing so unless they are directly asked about it as bodily reserve is considered to be a mark of self-discipline and control in palliative care (Livingston in Biehl and Petryna 2013). For Tswana healers in Botswana, pain is treated as a social pathology, a part of social experience unlike biomedicine where pain is just pain, an object in itself. However, the main focus on primary care and emergency as a vertical health care model leaves very little room to accommodate pain and symptom control (Livingston in Biehl and Petryna 2013). Thus, Livingston shows how cancer-related pain is culturally constructed and lived in Botswana where the family becomes the embodied voice of the patient in expressing pain while silence is practiced by the patient as part of a culturally motivated stoic disguise.

The non-disclosure regarding cancer represents an ironic aspect regarding the cultural meanings attached to the human body. For example, the body undergoes various rituals before the performance of last rites as per traditional Hindu practices. The family members guard the deceased individual's body from predators such as vultures between the time of death and

cremation. The body is bathed and dressed in new clothes and vermilion is put on the forehead. Although, it has been argued that these rituals are also performed for hygienic purposes and to control the spread of potential infections, these steps also symbolize the sacredness of the human body before performing last rites since the body is considered to be sacred. Thus, the family acts as the gatekeeper through embodying therapy management in life and ritual practices after death. This may beg the question that if the human body is sacred, then the person embodying it also has the right to bodily integrity which translates as having the right to know what is going on with their body? However, the issue of integrity is inadvertently juxtaposed with the issue of rights and ethics in the domain of social sensibility and medical practice.

Anthropology, Public Health and Collective Decision Making

Historically, anthropology as a discipline has been interested in examining value systems and has considered the evolution of morality to be continuous and culturally specific. Thus, anthropology views medical dilemmas and their ethical resolution as a product of culture which affects behavior related to health and illness (Marshall 1992). In addition, the rhetoric of analytical objectivity and individual rights is a means of disciplining the body as per Foucauldian analysis (Carson 1990 in Marshall 1992) where the autonomy of the body and how an autonomous body should behave is predominantly a perception of the Western construct of sovereignty. While this argument highlights the ethnocentrism that is prevalent in bioethics, it is not meant to beleaguer the significance of freedom of choice and individual will. However, it highlights the role of socio-cultural context in informing bioethics and decision making which is critical to the understanding of the dynamics that influence disclosure practices around cancer. In addition, health care providers, patients and families can negotiate therapeutic interventions as

part of a collaborative process although the differences in status and distribution of power among various stakeholders add another layer of complexity to the process of joint decision making (Marshall 1992).

Hence, being cognizant of the sociocultural context of the illness can be instrumental for understanding who and which viewpoint deserves precedence in a given situation. Similarly, a medical situation involving decision making regarding the disclosure of a cancer diagnosis can be an area of conflict and uncertainty for all parties involved. However, it may also potentially has the capacity to create an opportunity for conflict resolution by shifting the attention to the social aspects of illness and healing and not just the biomedical information regarding the disease. In addition, it encourages a biomedical environment that is sensitive towards the vulnerability of patients and families while reducing the powerlessness accompanied by a serious chronic illness such as cancer (Marshall 1992). The anthropological approach regarding bioethics and collective decision making calls for incorporating “ethno ethics”, a term coined by Lieban (1990) which pertains to inculcating awareness about cross cultural differences in medical ethics and the ways in which various societies define which issues deserve moral relevance or are viewed as problematic (Sharif and Bugo 2015).

Similar to anthropology, contemporary public health recognizes the challenges presented within the tenets of autonomy and self-determination within the bioethical framework. Several research studies within public health have focused on the medical and ethical dilemmas posed by the incongruence of a value system that views the practice of ethics from a unidirectional perspective, particularly when dealing with cross cultural populations. In addition, the autonomy centered approach of bioethics is perceived as paternalistic and imposing on populations (Bayer and Fairchild 2004). On the other hand, Callahan and Jennings (2011) have

argued that there is a fundamental difference between the conception of bioethics and public health practice.

According to Callahan and Jennings, “In early bioethics, the good of the individual, and particularly his or her autonomy, was the dominant theme, not population health” (2011). Thus, they view the formative difference between bioethics and public health as an “epistemological” obstacle given the focus of public health practice regarding societal benefit. Therefore, Callahan and Jennings suggest incorporating “applied or critical ethics” which focus on sociohistorical trends with regard to decision making and professional conduct during public health interventions and hence share a similar context with the concept of “ethno ethics” (Lieban 1990).

These discussions illustrate that the issues regarding collective decision-making and ethics is not just pertinent to only cross cultural populations. This is a dilemma that presents itself among patients, families and physicians who are affected by the complex interplaying dynamics of disease and illness in biosocial space. Hence, the responsibility of anthropology and public health as research disciplines and modes of practice is to turn the lens inward and redirect the dialogue on ethics and autonomy within scholarly and academic practice. Figure 1 illustrates a graphic representation of the theoretical elements discussed in this chapter and presents a blueprint for the interactions between various stakeholders in cancer disclosure and illness.

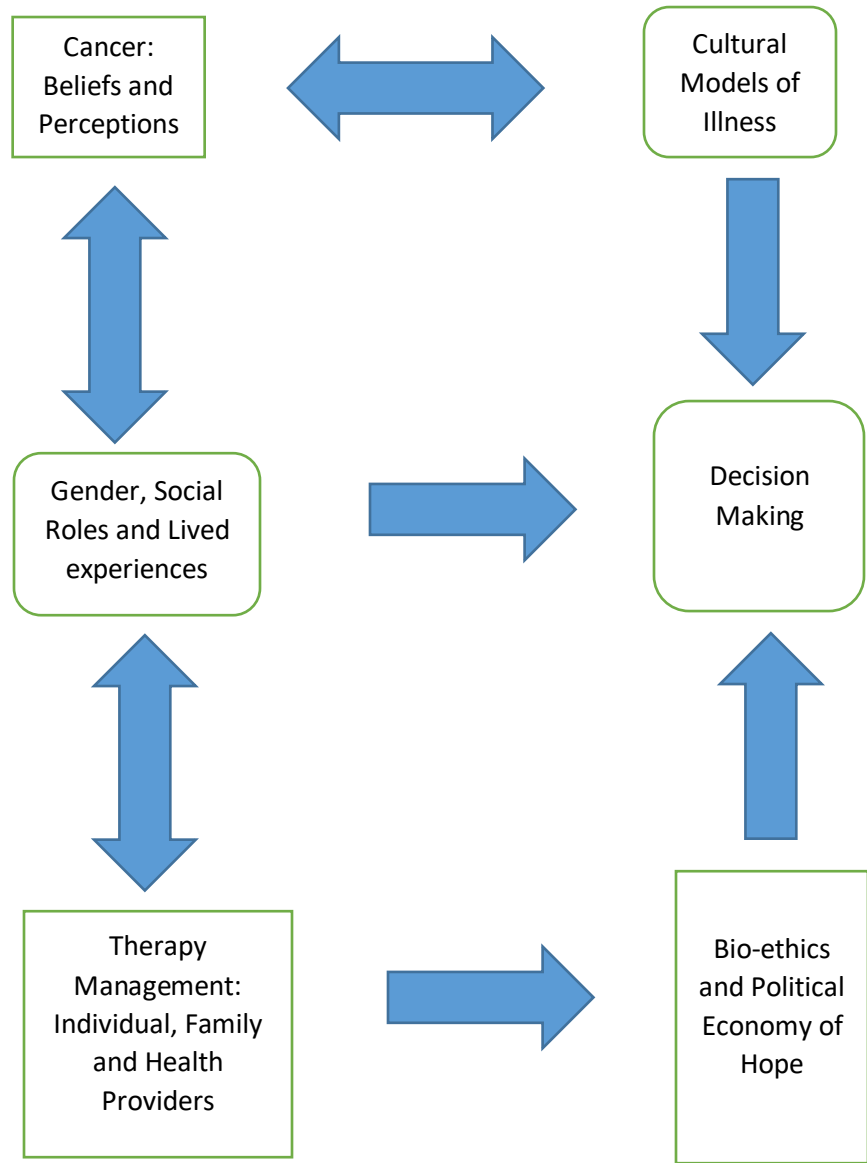


Figure 1: The theoretical connections flow chart depicts conceptual elements in cancer disclosure and illness.

CHAPTER THREE:

METHODS AND ETHNOGRAPHIC APPROACHES

Ethnographic Approaches

This project drew from a number of methodological approaches to explore the various ways in which a diagnosis is revealed and shared among patients/survivors and caregiving family members. It examined the collective impact of a cancer diagnosis and illness on the lived experience of individuals and family members. In doing so, this study also looks at the role of health providers in cancer communication among patients and families. In addition, it explored the moral ambiguities of sharing – or not sharing – a cancer diagnosis with the patient and/or family members and its impact on the personal experience of cancer and its larger connection to the discourse on bioethics.

Given the involvement of multiple stakeholders in the study and cancer as a sensitive and at times restricted topic of discussion in the Indian community, an ethnographic framework was deemed fit for exploring the experiences and interpersonal communication on cancer.

Ethnography as iterative-inductive research evolves in design throughout the study, drawing on a family of methods, involving direct and sustained contact with human agents, within the context of their daily lives and cultures (O' Reilly 2005). Hence, ethnographic research involves the study and conceptualization of complex and abstract socio-cultural phenomena embedded in cultural meaning systems. LeCompte and Schensul posit that “ethnography is a systematic

approach to learning about the social and cultural life of communities, institutions and other settings that are scientific and investigative” (2010). It focuses on the meanings that individuals assign to their lives while recognizing that these meanings are malleable and “locally specific”. Thus, ethnographic inquiry is an apt tool for studying complex and sensitive issues such as cancer, since it provides the interviewer and the interviewee with the opportunity to explore and share the diversity and complexity of human experiences focusing on what people do and why they do it.

Fine notes that it is the position of individuals in a social group that guides the interest of the researcher where the process of ethnography presents diverse human interactions in a social group (2003). Additionally, the intricate connection between human experiences and the socio-cultural environment also shape the direction of research. Hence, an ethnographic approach involves intimate and reciprocal involvement with community members, which calls for building trust and placing emphasis on the perspectives and meanings of participants with respect to their issues (LeCompte and Schensul 2010). Although conventional scientific inquiry emphasizes the notion of objectivity and distance, ethnographic research advocates for immersion in the world of participants as a way to understand the layers of meanings and subjectivities that inhabit their world. As Appadurai posits, “intimacy is connected with experience, particularity, embodiment, lived worlds and real lives reflecting that the best ethnography is about intimacy” (in Lamb 2002, 300). Thus, an ethnographic approach focuses on the lived experience of a particular community or individual(s), which makes it suitable for studying disclosure practices regarding cancer and the workings of collective decision making.

The anthropological stance on bioethics supports the inclusion of ethnography for the purpose of recognizing social patterns that embed ethics in institutional structures. In addition, it

urges ethicists to analyze moral phenomenology more closely and recognize the relationship between moral reasoning and social practices (Marshall 1992). However, the ethnographic method has also been critiqued for not having reliability since studies cannot be replicated in an exact manner (Schensul and LeCompte 2013). Nonetheless, ethnographic research provides a rich and multidimensional context to the study of human problems that are not static objects in controlled laboratory environments. Moreover, the reliability of an ethnographic study can be improved by returning back to the ethnographic site to explore whether the findings are still consistent or have changed over a period of time. Ethnographers can also improve validity by developing appropriate instruments, pilot testing their questions, and developing a rapport with their participants to prevent the relay of misleading information (Schensul and LeCompte 2013). With regard to these considerations, I had pilot tested the questions in the study during a small-scale, preliminary ethnography that I had conducted with 5 participants for a graduate course. In addition, I gradually developed and modified questions that were considerate and reflective of their experiences based on initial interviews during data collection.

Positionality, Reflexivity and Historicity in Ethnographic Research

According to Hirsch and Stewart (2005), “historicity describes a human situation in flow, where versions of the past and future (of persons, collectives or things) assume present form in relation to events, political needs, available cultural forms and emotional dispositions”. The premise of “historicity” is synonymous with positionality, since its usage suggests a reflexive approach to fieldwork given the presuppositions among the researcher and the community owing to respective sociocultural conditioning. In this sense, the concept of historicity focuses on the connection between past, present, and future and temporal knowledge.

Hence, the idea of historicity in ethnographic research can be useful in answering a fundamental question regarding cancer disclosure. For instance, why is non-disclosure of cancer prevalent among groups that have access to improved biomedical technology and treatment? In this regard, historicity is useful in providing content and context to ethnographic research as a reminder for paying attention to the transfer of knowledge, the formation of social memory and the ways in which beliefs regarding cancer and disclosure concretize among groups through the passage of time. It links the social production of knowledge through accounts of past, present and future.

As Hirsch and Stewart suggest, “To understand historicity in any particular ethnographic context, then, is to know the relevant ways in which (social) pasts and futures are implicated in present circumstances” (2005). Therefore, I have incorporated viewpoints on how the participants perceived and understood cancer as a disease and illness by framing questions related to family history of cancer and whether participants were aware of it? In addition, I asked participants to elaborate on whether a cancer diagnosis was discussed openly within their families or if there had been reservations? Additionally, how did the absence or prevalence of talking about cancer influence their own attitude towards it especially in cases where participants had been diagnosed with cancer later in life? My objective was to gain a perspective on what factors attributed towards shaping their opinions on cancer disclosure in relation to the concept of historicity in this regard.

The concept of historicity also relates to a researcher’s positionality regarding sociocultural background and how it is perceived by the community during ethnographic fieldwork. In particular, it has specific implications for studying a topic within a community of shared cultural background or where one would be considered a “native anthropologist,” as in

someone who is studying one's own community (Narayan 1993), such as in my case and hence might have the benefit of possessing a certain degree of cultural knowledge. However, Narayan reflects on the polarizing way in which the subject of the native anthropologist has been addressed in anthropological research in the past, and challenges the assumption that anthropologists studying communities from their native background are default insiders. The general assumption has been that the "native" or the "insider" anthropologists who study their own cultural backgrounds can approach their work with a certain ease and closeness.

However, cultures are neither homogenous nor static. Additionally, being in a position that explores the lived reality of communities creates a distance which challenges the presumption of being an "authentic" insider (Narayan 1993). This simplification negates the experiences and complex social factors that are part of a researcher's background. Narayan emphasizes that other factors such as race, education, gender, class, and so forth might outweigh the cultural identity that one associates with being an insider or outsider anthropologist. Simultaneously, the process of reflexivity involves a constant process of self-interrogation concerned with the production and source of knowledge in the field. Therefore, the development of subjectivity is multiplex and laden with overlapping identifications (Kempny 2012). The relationship between the researcher and the community produces data as a result of the anthropologists' participation in certain situations.

Hence, ethnographers aid in constructing situations or "systems of truth" that contain an exchange of history and power and eventually generate results for the study (Clifford in Kempny 2012), which makes anthropologists positioned authors who witness interactions among various social agents in the field (Okley in Kempny 2012). Narayan proposes that anthropologists have transitional identifications in their role as researchers as they negotiate their way through power

differentials within a community. At the same time, anthropologists are responsible for the representations of individuals whose narratives are brought to light and hence there is an ethical obligation to see beyond professional aggrandizement and present views and voices of those individuals even if they are critical of the discipline itself (Narayan 1993).

With regard to my own positionality as a researcher, a shared cultural background was useful in framing in-depth questions although there might have been the possibility of overlooking information that I may have taken for granted due to cultural familiarity. Apart from this, the sensitivity of the topic presented the likelihood of participants assuming that I would by default understand, agree, and empathize with their viewpoints and choices in a particular situation. This made probing for additional information at times harder since I did not want the participants to feel that I was detached or questioning their core beliefs and values regarding the matter. For instance, in cases where the participants had decided to be open about their cancer diagnosis, I had to be cautious about exploring their reason for that decision because I did not want to come across as presuming that they would conceal their diagnosis and as a result disregard the agency that they had expressed in making the choice to disclose their diagnosis. Alternatively, I did not want to appear insensitive by directly questioning the choice of not to disclose the diagnosis in cases where participants expected me to be empathetic about their decision because they considered limited disclosure as a thoughtful and considerate choice towards their loved ones.

Additionally, this study also explored the perspectives and experiences of health care professionals regarding cancer disclosure and ethical challenges associated with it, although such inquiries implied interviewing individuals with authoritative knowledge within a biomedical system. During the interviewing process, I had mixed feelings of apprehension and curiosity

with regard to how the medical professionals would receive my questions about cancer disclosure and whether they would be comfortable sharing their experiences about honoring family members' requests for non-disclosure or partial disclosure of a cancer diagnosis? Moving forward, I realized that I had to overcome my concerns and ask targeted questions about whether the medical professionals in my study had considered requests for non-disclosure of a cancer diagnosis anyway since I my objective was to gather a well-rounded perspective on cancer disclosure from health care providers in addition to patients/survivors and family members.

Also, the position of conducting research among a population with social privilege and clout is not uncommon in anthropology. Paget (1993) wrote about her own experiences as a cancer patient with medical authority in relation to a false diagnosis in "A Complex Sorrow: Reflections on Cancer and an Abbreviated Life (in Cassell 2002). Additionally, Chrissler et. al write about authoritative knowledge and its ability to exercise power as a representative state power through the case of Turkish doctors who could exclude men from military service based on sexual orientation. Hence, I had to be cognizant of framing my questions in a thoughtful manner that focused on the experiences of health care providers instead of coming across as unintelligible or intrusive. For example, instead of asking directly, "Have you ever had a case where a family member has asked you to withhold a cancer diagnosis from a patient"? I would often begin my question by stating that, "I understand that dealing with an illness such as cancer is not easy since you are often dealing with situations that can be very sensitive".

These instances elucidate some of the intricacies of interviewing participants from two distinct groups where I expected the patients/survivors and family members to have a more empathetic approach towards non-disclosure while I expected the health care professionals to have a more objective approach towards cancer disclosure given their professional background.

However, conducting research in a mixed group of participants also presents the opportunity for producing enriching and in-depth research that presents multiple perspectives on an issue. Moreover, anthropological research needs to concern itself with “studying up, down and sideways” to explore the various characteristics of power (Nader 1996 in Grandia 2015). Therefore, a researcher needs to judiciously consider the receptiveness towards the researcher, the framing of information and whether a collaborative exchange of knowledge can occur. In addition, insights on cancer disclosure from health care providers and other health professionals deserve attention given the interconnectedness among patient/survivor needs, caregivers and clinical treatment.

Qualitative Approach to Studying Cancer Communication and Illness Experiences

Various research studies regarding the study of cancer disclosure, collective decision making, and other cancer related issues in the literature have employed qualitative ethnographic methods that included participant observation, focus groups, case studies, and semi-structured interviews. Many studies have also used quantitative and mixed methods, which included quantitative surveys and analysis in addition to qualitative methods (Montazeri et. al 2009; Akabayashi et. al 1999; Strasser et. al 2007).

Qualitative methods in particular are highly instrumental in exploring the subjective experiences regarding chronic, advanced and restrictive terminal illness (Kvale et. al, 2010). Qualitative research helps to identify the processes influencing perceptions of reality, and how individuals construct meaning and interpret events in their lives. Also, qualitative methods are useful for studying a sensitive topic that requires in-depth information and analysis. A semi-structured and open-ended style of interviewing enables the researcher to probe information in

detail and frame further queries based on the interviewee's answers (O'Reilly 2005). Semi structured interviews draw upon specific instances and experiences in a guided but flexible manner that are relevant to the subject of the study (Schensul and LeCompte 2013). Likewise, Bernard (2006) emphasizes that semi-structured interviews provide the opportunity to have an unrestrained conversation with the participant, and aptly fit research designs that deal with culturally sensitive or difficult topics. In addition, they help to locate themes and patterns in qualitative data (Schensul and LeCompte 2013: 172). Hence, in-depth, open-ended interviewing is a feasible method for obtaining data that concerns sensitive issues such as stigma, terminal illness, and health-related beliefs in general. Also, one-on-one interviewing enables clarification of responses and modification of research questions when necessary and allows participants to respond freely (O'Reilly 2005). It makes it possible to gauge the participant's body language or facial expressions which may provide additional cues about the participant's emotions during the interview.

A Note on Loss and Grief in the Field

As I write this, one of the study participants has passed away, while two others might not be around for long. When I started the study, my thoughts were focused on experiences and narratives of cancer among the selected population in the study. To prepare, I would practice explaining myself to my participants regarding the objectives of the study to appear less intrusive, since they would be sharing sensitive details regarding an illness that not everyone was comfortable talking about in the community. In framing experiences of cancer as stories of cancer to myself and my participants, ironically death and dying seemed like a distant possibility. As a result, I was not well prepared to deal with the possibility of it actually happening.

Moreover, I had habituated myself to collecting experiences of cancer as a cerebral process in graduate school given the immersion in literature and completion of preliminary assignments and hence obtaining knowledge was the primary focus of my intellectual attention.

As I began interviewing, the emotional process of exposing myself to the pain, suffering, and loss of other individuals slowly began to seep in, even though I felt empowered, inspired and honored by my participants' stories of being able to endure and share with me their unimaginable experiences of both heart wrenching despair and relentless optimism in dealing with cancer. In addition, I also experienced validation, since their stories gave intellectual meaning and purpose to my research. While feelings of joy and empathy were frequent visitors that mirrored what my participants felt in relaying their triumphs and tribulations with cancer, grief was something that I had neither experienced nor foreseen until Simi passed away. I had been introduced to Simi through a common friend. Simi had been diagnosed with cancer a few years prior and had seen her cancer return after going into remission.

Simi was passionate about telling her story and for her story to be known. She believed that anyone who wanted to talk about cancer had the right and deserved the opportunity to do so, given her own family's reserved approach towards openly sharing a diagnosis of cancer. Apart from graciously sharing her experiences with her illness and her perspective on cancer disclosure, she also eagerly shared her hobbies and her aspirations with me. Her narrative had a sense of optimism but also a calm acceptance of what she was going through. It seemed like she was facing a temporary block towards her recovery at the time but was eventually going to be okay. My interactions with her gave me a semblance of a friendship and a connection that I could possibly build beyond the interviewer/interviewee relationship. During our last conversation, we talked about her visiting Atlanta when she felt better and decided to chat again over the weekend.

However, Simi passed away that very weekend, owing to deterioration in her health. Even though I was aware that death might be a possibility, the news of her passing felt like a stranger had knocked on the door unwelcome and uninvited. I remember feeling frozen, bizarre and helpless on a sunny afternoon when I received the phone call. It seemed like the sky had turned into a dense sheet of ice with the sun burning through it like a brazen ball of fire. I felt I had lost a friend that I could have had. I had lost the opportunity of learning and knowing more about our common interests. I felt powerless about not even being able to express my condolences to her family, since she had shared that certain close family members were not too keen on her talking about her illness but she had taken the decision to do so anyway. For the next couple of days, I began frequenting online platforms where she had interacted and posted content and told me about, in a bid to construct and know a person that I now knew I would not get to know. More than anything else, I had desperately hoped that Simi would live for her family that she so lovingly doted on and cared about. More so, her passing felt like a failure, because I had learned that anthropologists strive to forge long-term bonds with community members but in this case, a channel was closed and a bond was severed for good. Simi's passing felt like a personal loss and a professional stalemate.

I learnt that the mental process of immersing oneself in anthropological literature and training was still separate from the emotional process of being in the field. While the traditional approach in scientific training and research methods has leaned towards adopting and imbibing a detached outlook towards the emotions of the researcher, it is the attachment towards a particular field that often drives researchers to pursue an area of interest (Cain 2012). Hence, acknowledging one's emotions in fieldwork might actually improve the quality of one's research

although researchers often receive little training regarding dealing with the emotional impact of their research during fieldwork (Cain 2012).

Additionally, I think it is hard to predict the exact ethical conundrums that are going to appear in the field even if a researcher is expecting them because research studies often present unique situations pertinent to that particular topic and population. This often adds to the stress of dealing with the emotional implications of researching a difficult area of study and coping with feelings of inadequacy that might arise in the face of unforeseen emotional and ethical dilemmas. Moreover, Cain argues that we do not have to “disentangle ourselves from those we study” in her study of hospice workers (2012). If anything, the discipline of anthropology emphasizes immersion as a strategy in qualitative fieldwork (Geertz in Grieve 2010). My research experience has helped me to impart an additional layer to the understanding of immersion where I was finally able to accept and embrace the grief instead of fighting it; and arrive at an emotional and intellectual juncture of presenting stories as a non-detached observer and storyteller.

The Research Setting

A Demographic Overview of Indian Immigrants in the United States

Indian immigrants have a significant presence in the United States and are affiliated with diverse multicultural, regional, and socio-economic backgrounds. British colonialism was one of the factors that contributed towards the immigration of Asian Indians to the United States. Certain non-farming communities were restricted from owning agricultural land under the Alienation of Land Act in India under the British colonial empire (Alagiakrishnan and Chopra 2001). This led to the migration to the United States of approximately 3000 Asian Indians belonging to a farming background. A legislation passed in 1946 granted Asian Indians the right

to American citizenship, which enabled them to sponsor family members from India to the United States (Alagiakrishnan and Chopra 2001). In addition, the Immigration and Naturalization Act of 1965 facilitated the immigration of various immigrant groups including Asian Indians who had a specialized skill set (Bhalla 2008). There has been a significant growth in the Indian American population in the past ten years exceeding other Asian groups according to the census data from 2010 (New America Media 2011). Indians are the third largest ethnic group from Asia living in the United States (Sharma and Kemp 2012). Asian Indians are also the largest Asian subgroup in 19 of the 26 states, with a prominent presence in the Midwest and the South in the United States. In particular, the Indian American population has increased by over 80 per cent in Florida, South Carolina, Tennessee and Kentucky while their numbers have doubled in Georgia since 2000 (New America Media 2011).

The Primary Research Site

The primary research site for the study was Atlanta, Georgia, a city with a substantial population of Asian Indian immigrants marked by the emergence of cultural associations, places of worship, and local radio and cable channels. Based on 2000 census data, Asian Indians are demographically present throughout Atlanta, but are heavily concentrated in Fulton (4200), Gwinnett (6600), Dekalb (4700) and Cobb (3800) counties. As per the 2000 data on labor, Atlanta's businesses that require an expertise in IT (Information Technology) have been a source of professional attraction for many Asian Indians. Many Asian Indians are also employed in the field of medicine, business, finance and management (Atlanta Regional Commission *n.d.*). Also, I had conducted fieldwork for my thesis research for my masters' in Anthropology in Atlanta, which enabled me to establish a rapport with the local Indian community. Preexisting

relationships in the field were highly instrumental in recruiting participants through referential sampling and especially while collecting data on a sensitive topic.

Asian Indians are the most predominant immigrant group among Koreans, Vietnamese and Chinese in Atlanta, Georgia (AARP 2013). 38 per cent Asian Indian men and 25 percent Asian Indian women have a graduate or professional degree and 71 percent Asian Indian men and 63 per cent Asian Indian women have a bachelor's degree over the age of 25 (Atlanta Regional Commission *n.d.*). The median household income among Asian Indian families is \$60,800 (Atlanta Regional Commission *n.d.*). A significant number of Asian Indians belonging to highly educated and professional backgrounds have been attracted to Atlanta due to the emergence of a prominent Information Technology (IT) sector (Atlanta Regional Commission *n.d.*). 3,700 Asian Indian men and women are employed in occupations related to IT and mathematics representing 21 percent of the field's workforce while management, business, finance employ 2700 Asian Indians. Simultaneously, 4500 Asian Indians are employed in sales and office administration and 440 Asian Indians are employed as physicians and surgeons in the greater Atlanta area (Atlanta Regional Commission *n.d.*).

Addressing Participants as Cancer “Survivors” or “Patients”

The population of individuals diagnosed with cancer who is cured, in remission, or living with cancer has increased and continues to grow given the improvement in medical technology and treatment. The 5-year survival rate for patients has increased from 50% in 1975 to nearly 70% in 2006 (Dirvin et al 2015). The population of individuals who had survived cancer for five years since diagnosis was estimated to be 30 million worldwide in 2012 (Dirvin et al 2015). The

number of individuals diagnosed with cancer or who previously had cancer was 14.5 million in the United States in 2014. This population could increase to 19 million by 2024.

Given these statistics, there is no single universally accepted definition of a cancer survivor. For instance, the US National Association of Cancer Survivors (NCCS) defines a cancer survivor as an individual from the point of diagnosis to the remaining period of their life. The US National Cancer Institute (NCI) extends this definition to family members, friends and caregivers since they might be affected by the survivors' experience. The European Organization of Research and Treatment of Cancer Survivorship Task Force (EORTC) views any individual as a survivor who has received a cancer diagnosis, completed primary treatment excluding maintenance therapy, and has no evidence of recurrence (Dirvin et al 2015). Alternately, individuals with a cancer diagnosis are also referred to as cancer "patients" while in treatment and are considered to transition to survivorship once they complete it (Garofalo et al 2009).

Considering these variations, throughout I refer to participants as patients/survivors or individuals who were diagnosed with cancer. In addition, at least one participant expressed her disapproval to the use of the term "survivor," since she felt that it is a permanent label that she had to live with for the rest of her life and that the term should not define her. In her words, "I don't know why we say 'survivor?' I do not like this word. I don't like to think about cancer. I am done with it."

Her comment did raise some very crucial questions about the framing of the term "cancer survivor," survivor identity, and the agency of individuals to receive it or reject it regardless of how the medical community and researchers frame it. Similar experiences have been noted in cases of childhood cancer (Jones et al 2011) where the label of survivor is viewed as either invasive or liberating (See Smith et al 2016). According to my participant, she was not a cancer

patient anymore and she did not have to think of herself as a survivor since cancer was like any other disease. Hence, I have included the words “patients/survivors” and “individuals with cancer” as a way to reflect multiple viewpoints on the use of these terms and to honor my participants’ feelings even though, it was not within my scope to explore issues related to survivor definition and identity among participants during this study.

Experiences Regarding Translation during Data Collection

The participants spoke both Hindi and English and often switched between these two languages during the study. Hindi is one of the prominent official languages of India which is predominantly spoken in North India. However, it is also prevalent in other parts of India along with different languages and dialects that are native to specific regions within India. While some participants were more fluent in Hindi than others, all participants were conversational in Hindi in spite of hailing from different parts of India though this might not always be the case. For this study, I translated participant narratives in Hindi wherever applicable.

Additionally, in terms of translation, I did not face any major language barriers in terms of understanding participant narratives as a native speaker of Hindi myself. However, as Nes et al note, the differences between two languages also imply the differences between the understanding of certain concepts and contexts in those languages. This is particularly of consequence in qualitative research given that language occupies the center stage from data collection to analysis and the publication of findings (Nes et al 2010). Given this, I had to be conscientious about translating the participants’ linguistic expressions from Hindi to English as closely as possible to the meaning and emotions that they were presenting through their narratives. For this purpose, I have translated the participants’ statements in English in

parentheses whenever they spoke in Hindi to preserve the emotion and context of their narratives. For example, here is an excerpt from one of the participants, Alex who was sharing her experience of cancer with me during the interview.

Alex - *Ghabrahat hoti thi. Kuch khane ko man nahi karta tha* (I used to feel restless/nauseous. I used to not feel like eating anything) with chemo.

Here, the word *ghabrahat* in Hindi could imply restlessness, anxiety, nausea or experiencing palpitations or a fast heart beat/heart rate depending upon the context of the sentence. However, expressing this in English was a challenge because I knew that Alex was sharing this experience from an emotional standpoint as well as the physical impact of chemotherapy on her body given the complete context of this conversation. Hence, the closest that I could relay the meaning of her words and her experience was by using both words “restless” and “nauseous” for the use of the single word *ghabrahat* in this regard. However, in one of the other instances, Alex used the same word *ghabrahat* while sharing that her daughter would switch off the television during a sad or dramatic scene while watching a movie or series “*ke ghabrahat na ho jaye*” (so that, I do not feel restless). Here, Alex was clearly referring to *ghabrahat* in terms of emotional impact on her senses and hence, I have used the word restless to translate the context of her statement.

Research Design

This study was designed as a qualitative research study that recruited thirty five participants (n=35) via referral sampling primarily from metropolitan Atlanta, Georgia as well as other regions of the United States since it was challenging to find sufficient participants due to the sensitive topic of research. The study recruited participants who identified themselves as receiving a diagnosis of cancer, or had a close family member who had been diagnosed with cancer. In addition, the study recruited a smaller sample of health professionals (n = 5) regarding perspectives on disclosure of cancer. The study also incorporated archival research from social media platforms, news articles, and blogs. The Institutional Review Board (IRB) at the University of South Florida approved this study.

Methods

Semi-structured Interviews

This study incorporated semi-structured interviews, which addressed a range of questions and topics through open-ended questions to facilitate free exchange of information (Bernard 2006). The semi-structured interviews in this study drew targeted information on perceptions and metaphors regarding cancer and the medical history of participants. The interview guide for participants included generic background questions such as their age, education, income bracket, marital status, immigrant status and number of years that they had been residing in the United States. The questions concerning medical history included information about family history of cancer, type of cancer and the duration of cancer treatment. More specific questions on the topic included asking the participants about when they or a family member had come to know about their cancer diagnosis? Did the participants deal with any specific emotional and financial

challenges and whether there were internal and external forms of support from family members and professional services?

Additionally, I also asked participants about their perceptions regarding cancer as a disease and if they had any specific beliefs about causation in addition to the biological mechanisms that cause it? Most of the questions were similar for health care providers in terms of general background and beliefs about cancer. However, the interview questions with participants differed in terms of inquiring about requests regarding non-disclosure from patients/survivors or family members and their perspective on the issue of cancer disclosure. These questions were overall more open ended and I framed my subsequent questions based on participant responses. Nonetheless, in-depth, open-ended interviewing was the most appropriate method for obtaining data on the sensitive issues of health and socio-cultural beliefs related to cancer disclosure in this study.

Sampling

The semi-structured interviews were conducted among 35 participants (n=35) which included 30 patients/survivors and family members (n=30) and 5 health professionals (n=5). Two of the participants among patients/survivors were also able to provide their views as health professionals. The health professional interviews were instrumental in obtaining comprehensive and well-rounded perspectives on cancer disclosure, bioethical issues and the role of family members in caregiving as seen by health care providers. The participants were recruited through referential sampling, as I had prior experience in conducting research at the site. In referential sampling, a few key contacts who are already known to the researcher aid in enlisting other participants (Bernard 2006).

Data Collection

The interviews were conducted at a location that was convenient and private for the participants, such as their residence. The interviews lasted for approximately 45-120 minutes, and were recorded on a secure audio device with the verbal consent of the participants. The interview guide contained open-ended questions, which focused on specific topics concerning beliefs about cancer, disclosure of diagnosis and the overall lived experiences of cancer-related illness.

Data Analysis

This study incorporates Kleinman's perspective on the social meanings of illness and patient narratives as a way to understand the lived experiences of cancer patients and caregivers. I color coded dominant themes in the transcripts in Microsoft Word. For example, I assigned the color yellow to any information related to disclosure which included phrases such as knew, did not know, should tell, did not tell, told everyone, told a particular relative were assigned the color yellow. Given that disclosure patterns were the primary dominant theme in the research objectives and presented different patterns, I separated the responses based on three categories of full disclosure, partial disclosure and non-disclosure of a cancer diagnosis. The categories of full and partial disclosure implied that either the participants had received and shared their or a loved one's diagnosis with everyone or a limited number of individuals. Simultaneously, non-disclosure included specific instances where the participants did not know about their own diagnosis or had chosen to not disclose the diagnosis to a patient/survivor as a family member.

Additionally, any quotes that contained information regarding caregiving and the emotional and physical effects of cancer were assigned the color green. Similarly, I assigned the

color purple for themes related to god, faith, religion, culture and philosophy. Following this, I organized the quotes under each color coded theme to look at overlapping information in the data. Based on that, I organized the chapters and added notes on how those themes related to existing literature and the information that they presented regarding cancer disclosure patterns among participants and subsequent sub themes such as participant perspectives on caregiving, role of religion/spirituality in coping with cancer and their views on ethics in relation to cancer disclosure. Additionally, all transcripts and notes were entered in Max QDA, a qualitative data analysis software and were coded based on thematic domains for words tell, not tell, care, loss, god, faith, legal etc. The MAXMaps feature was used to view the visual connections in dominant themes. The use of color codes that I had originally used for manual analysis was also beneficial in MAXQDA to look at the distribution of themes in the transcripts. Although my primary form of analyzing the transcripts was manual, I used MAXQDA to verify the emergent themes in my analysis and ensure that I did not miss any overarching key themes and sub themes in the study.

Participant Observation

Participant observation entails complete immersion in a culture, and framing it in an intellectual perspective (Bernard 2006). Conducting conventional participant observation was challenging for this study since I collected the data via one on one interviews considering the sensitive content of conversations and the variation in attitudes towards discussing a cancer diagnosis and illness experiences. However, I observed online interactions among open groups on Facebook and Instagram such as Yoddhas, a cancer support group based in India. Similarly, the MAX Foundation sponsors an event “Chai for Cancer”. Both tea and coffee but more so tea occupies an undisputed cultural prominence in Indian culture. It is a beverage that is eagerly

consumed in most personal and public spaces across India. Issues that are mundane and important such as marital alliances and political discussions occur around tea. Volunteers often serve tea and snacks at a residential or communal venue to meet and talk about cancer. “Chai for Cancer” provides an open platform to individuals and families affected by cancer, health professionals and the general public to share experiences and awareness about cancer.

Data Management Plan

The data was stored electronically as MS Word files protected by a password. The data will be stored for five years and will be accessible to participants who are interested in insights from the study.

Ethical Considerations

The study was conducted after the Institutional Review Board (IRB) approved the research proposal. In addition, the participants were ascribed pseudonyms to protect their privacy. The participants were granted complete information outlining the study’s objectives, protection of their personal information, and any kind of risk associated with the study. Waiver of written consent was obtained from the IRB following the discomfort expressed by some of the participants towards signing the consent form for the study. All participants provided their voluntary and informed verbal consent. The participants had the choice to not answer a question or reveal personal information that they were not comfortable sharing with the researchers. The participants reserved the right to not participate in any of the research related activities if they did not feel comfortable. The participants could voluntarily withdraw from the study at any given time when research was being conducted.

Table 1: Demographic Characteristics of Participants

<i>Total number of participants</i>	N = 35
Patients/Survivors	12
Family Members	18
Health Professionals	5
 <i>Sex</i>	
Male	4
Female	31
 <i>Age</i>	
21 - 40	9
41 – 60	15
61 – 80	11
 <i>Education level</i>	
High School and below	3
Associate's/ Bachelor's	12
Master's and above	20

CHAPTER FOUR:

NARRATIVES OF CANCER DISCLOSURE

Patterns of Disclosure

Munro et al (2014) define disclosure as the degree to which individuals who have been diagnosed with cancer prefer to discuss their emotions and opinions regarding the disease with other members of their social group. Although the disclosure of a diagnosis to one's loved ones is considered to be one of the most difficult emotional challenges of dealing with cancer, disclosure in itself varies in practice among various socio-cultural groups. Cancer disclosure has been broadly classified into three types. The full disclosure of a diagnosis refers to the individual having complete access to his/her health information following which it is the patient's prerogative to share that information as per their choice. Partial disclosure refers to a situation where a patient chooses to receive limited information from family members or health care providers about the diagnosis and prognosis of cancer (Miyata et al 2004).

Lastly, non-disclosure refers to a situation where patients have expressed that they would not like to receive any information about their own diagnosis. In such cases, patients have been known to assign that responsibility to a family member. Additionally, non-disclosure refers to the withholding of information from an individual who has been diagnosed with cancer (Chittem et al. 2013). The perception of cancer as "a death sentence" and the extreme fear associated with its prognosis is seen as a justifiable excuse for non-disclosure on grounds of compassion and protection from the "bad news" of having cancer. In addition, family members often act as

gatekeepers in handling health related issues for the individual ranging from dissemination of information to decisions regarding treatment (Chittem et al. 2013).

The narratives on disclosure of a cancer diagnosis here include participants who were either diagnosed with cancer or had a close family member diagnosed with cancer. In the latter case, participants shared deep empathy and closeness with those family members, and most of them had stake as caregivers and/or decision makers for the patient and hence provided relevant insights regarding disclosure and its role in shaping the experience of cancer illness. The following disclosure patterns emerged when I asked participants about how they communicated or came to know about a cancer diagnosis concerning themselves or a family member. In doing so, my intent was to examine how a conversation about cancer disclosure came about, how participants dealt with it and how that conversation established the role of various stakeholders in the decision making process following the diagnosis.

Cases of Partial and Full Disclosure

In certain cases, participants who were patients/survivors usually knew about their diagnosis directly from the physician and then it was their decision to share that information in ways that they considered to be appropriate. In select cases, the participants came to know about their diagnosis along with select family members, and then a decision was made regarding the extent to which that information would be shared with other family members or the wider social circle. I have categorized these narratives under partial or full disclosure since the patient/survivor knew about the cancer diagnosis and the decision to share it either openly or in a restricted manner.

Cases of Non-disclosure

Certain participants who were family members shared that they at times chose to not share the diagnosis with the patient because they had access to that information under specific circumstances. In other cases, neither the participants and nor the patient knew about the diagnosis initially and the dissemination of that information depended on other family members. I have categorized these cases under non-disclosure since the patient/survivor did not know about the cancer diagnosis. These narratives present the various factors that influenced how patients/survivors and family members handled a cancer diagnosis, and the power structures and social meanings that surround cancer communication and illness.

Familial Altruism in Cases of Non-Disclosure of a Cancer Diagnosis

The following vignettes illustrate the non-disclosure of a cancer diagnosis by family members in order to shield patients from perceived distress and anguish that the family members anticipated for them. Participants described how they would urge health care providers and other medical staff to not use the term “cancer” during medical appointments and treatment, asking them to describe the condition without using the word cancer.

Charu - He did not know. We did not tell him. I told the doctor to not tell him. He knew the word ‘cancer’ but he did not know the word ‘oncology’ and he did not ask me. He had some pain and he thought we were seeing the doctor for that. I did not tell him because of his personality. People here do not lie so I told the physician to use any term but not the word cancer.

Charu's husband was diagnosed with cancer. During the appointment, Charu had requested the attending physician to withhold the information about the diagnosis from her husband. In addition, she had expressed her wish to personally reveal the diagnosis to him. Charu's statement that, "People here do not lie" shows how family members navigate the ethical expectation of providing the diagnosis to the patient while honoring the wishes of the family member. Similarly, Seema, whose father had been diagnosed with cancer, shared that the physician left it to her to tell the diagnosis to her father since she was his primary caregiver.

Charu - The doctor left the decision to me. My brothers and sisters said, 'Why tell him? Do not say cancer.' The doctor would let me decide and not talk in front of him. I told him to use a term which he would not know. I was also just dealing on my own. I did not share. I did not expect help. My mom knew about my father's diagnosis. For a year and a half, she was hopeful. By second round of treatment, even he knew.

Seema's case illustrates the collective decision on part of her family to not share the diagnosis with her father. It also presents a situation where family members might be willing to share the diagnosis once the patient's chances of survival improve. It also provides an insight into Seema's state of mind, as she was not willing to talk about her father's diagnosis while dealing with her emotions regarding the illness. Thus, apart from reasons of empathy and compassion, the non-disclosure of the cancer diagnosis to the patient and in wider social circles often results from self-withdrawal as a coping mechanism to process and cope with the reality of a loved one having cancer.

Nita echoed similar sentiments. Her father was diagnosed with cancer. She was one of the primary caregivers for her parents. She often tended to their personal and medical needs in terms of helping them with errands, shopping for groceries, cooking and driving them to doctor's appointments. She came to know about her father's diagnosis at one of his medical checkups and decided to not to tell him about it. Her father had a language barrier with regard to understanding the American accent and hence, she often communicated on his behalf with the medical staff.

Nita – We don't tell, we don't talk about it. When I came to know, I was also shocked. I told the doctor not to tell in front of him. He knew English but he sometimes did not understand the accent. Only my siblings knew. Even my mom did not know. It's not like the 60s. Americans know Indian culture too.

When I asked Nita about how it was possible for her father to not know his diagnosis in a clinical setting, she responded that she would signal the attending medical staff to not say anything that directly implied that he had cancer. This meant that they could still state what they were doing as long as they did not mention the word "cancer". In addition, Nita was the primary contact of communication between her father and the medical staff and hence relied on her to convey the information to him.

Nita - If someone said anything by mistake, I would signal them to not say something. They started giving him shots every couple of weeks. I did not tell him. I told him that he was being treated for something else. He would not have agreed for surgery anyway.

Nita's statement and the participant accounts show that the non-disclosure of the cancer diagnosis also extended to the non-disclosure of the treatment, since the patients did not know what they were being treated for in certain cases. This tended to occur mostly in cases where the family members were concerned about the patient being elderly and hence considered him to be too fragile to handle a diagnosis of cancer. In addition, non-disclosure was not just limited to cancer. Nita shared that she was not feeling well one day while she was taking care of her father. However, she did not share that with her family as she did not want them to get worried for her. Even though Nita's illness was not as serious as cancer, this instance shows that Nita tended to equate the non-disclosure of illness with compassion, irrespective of whether that compassion was directed at her father in the non-disclosure of his cancer diagnosis or the non-disclosure of her own illness to her family who were already concerned for her well-being since she was going through an emotionally draining experience as a caregiver and a daughter.

Nita's narrative about the non-disclosure of a cancer diagnosis to her father as well as her mother demonstrates familial altruism on two levels. Her father was the primary receptor of familial altruism given that he is the patient. Her mother was the secondary receptor since she was not the patient but Nita and her siblings anticipated a deep detrimental impact on her physical and mental health due to shock and trauma had she known about her husband's diagnosis. In addition, Nita's statement about Americans knowing Indian culture since it is not the 1960s highlighted the existence of partial and non-disclosure of a cancer diagnosis for a limited section of the Indian population. Her statement shows how articulating a particular disease is viewed as a part of a certain culture where the participants differentiate it from what they consider to be the larger American culture where the conversation around cancer is supposed to be more open in comparison to their own culture. This notion was not only present

among participants who did not disclose the diagnosis to the patient but also in cases where the patient knew about the diagnosis, such as in Leela's case.

Leela – We did not tell my father-in-law initially but we told him after a week. *Yahan aisa nahi hota. Wo India mein hota hai ki nahi batana. Yahan chupa nahi sakte*” (It does not happen in U.S. It happens in India where people do not tell. You really cannot hide it here).

Nita's and Leela's statements about “we don't tell” and how it is not possible to withhold a cancer diagnosis from the patient in the United States posits the disclosure of cancer as a cultural practice (“we don't tell”) that they see possible in India but not in the United States. In that regard, the decision to disclose or not disclose a cancer diagnosis is malleable depending upon place and context such as the perceived openness regarding the discussion of cancer and the norms regarding the disclosure of health information in the United States. In such cases, the health care providers were often willing to acknowledge the positioning of the family members as caregivers and decision makers for the patient. Hence, such situations implied that there was an understanding between the health care provider and the participants regarding a window of time in which either the family members would relay the diagnosis to the patient once they themselves would have absorbed the reality of the patient's diagnosis. Alternatively, the patient would come to know the diagnosis at some point but might not be severely affected by this knowledge since he/she would already have been under treatment and might suspect or know the diagnosis. Thus, the period between the diagnosis and treatment would serve as a block of time

where the patients would eventually figure out that they had cancer while the family members could avoid breaking the “bad news”.

In this regard, the site of clinical treatment also served as a buffering zone for the patient and the family members to come to terms with cancer while resolving the dilemma of relaying the diagnosis to the patient. In such cases, the health care providers often tried to reconcile the multiple and opposing expectations placed upon them. The requests regarding not to use the word “cancer” and yet fulfill professional responsibilities was a means to honor the family’s wishes, blunt the possible detrimental impact of the diagnosis on the patient’s well-being and yet fulfill the bioethical obligations by talking about the condition and treatment to the patient. These vignettes illustrate how participants navigated between their own understanding of dealing with their family member’s illness and the norms of medical practice regarding disclosure of medical information in the United States. They demonstrate the ways in which family members transgress medical authority by negotiating the conversation on cancer. They represent a dialectical narrative of cancer where family members play a crucial role in devising strategies in the expression and experience of cancer. These cases show how the term “cancer” itself is extremely emotionally charged and fraught with negative meanings for participants and presumably for the patients. Hence, these narratives illustrate how participants use semantics and language to approach and influence the dialogue on cancer among the patient, themselves and the health care providers.

The participants also shared instances where it was the participant who did not share a diagnosis of cancer, such as in Simi’s case. Simi was unaware of any family history of cancer since it was not a topic of open conversation in her family.

I felt a painful lump. I thought it was just a cyst. I waited for a few months which one should not do. I did not share this with anyone for three to four months. Our families don't tell. One of my relatives was diagnosed but I was never told. She had undergone a mastectomy. I did not know. I had no idea that there was a family history of breast cancer. I was just told that there is no family history of breast cancer whenever I would ask my parents or anybody else in the family. No one suspected anything because there was no (known) family history.

When I asked Simi if she thought that the lump might be a symptom of breast cancer, she replied that, "The thought crossed my mind but I thought it was a cyst. Maybe I was in denial".

Simi's case has particular implications for the significance of exploring cancer disclosure patterns and cancer communication. Her emphasis on "we don't tell" places cancer disclosure as a collective practice and decision within the bounds of a family unit. However, even though there are cultural dynamics to the non-discussion of cancer in certain families, which emerge out of the sentiment to shield the patient from perceived trauma and detriment to the individual's well-being, the delay in receiving medical attention can have far reaching consequences for the patient and their family. Simi passed away after a prolonged illness with cancer since it had reached an advanced stage. Simi's case also illustrates the significance of having awareness regarding a family history of cancer which tends to be clouded owing to a lack of discussion regarding cancer among certain families.

While Kate's mother knew about her diagnosis, Kate shared that she refrained from disclosing any other health conditions that her mother was diagnosed with during treatment.

According to Kate, her mother was not in a position to cope well with any additional health issues given that she was already physically and psychologically affected by cancer. For instance, her mother had developed a step infection during treatment but Kate had not told her about it. Kate also shared that she had actually requested the doctor to not even let her mother know about the cancer diagnosis. However, after an initial period of abiding by Kate's wishes, the doctor had disclosed the diagnosis to her mother at the time of surgery citing legal reasons.

She also had step infection. I did not tell her. All those things the doctor and I handle. Her nature is she gets very tense. She is diabetic too. She won't sleep in night. In the beginning, I told doctor, don't tell anything. During surgery, doctor said we have to tell per law. I came to know during mammogram. I told her may be cancer.

Kate's experience provides an insight into the multiple layers of non-disclosure among cancer patients and their caregivers. Kate considered her mother to be of a nervous disposition and hence did not want her physician to disclose the cancer diagnosis to her. She told her mother that it might be cancer during the mammogram but her mother did not receive a confirmed diagnosis until she was scheduled for surgery. However, Kate decided to not share any subsequent health issues that her mother had during treatment citing her anxious nature. Apart from Kate's concerns regarding her mother's reaction to her illness and multiple health conditions, her approach towards non-disclosure also sheds light on how family members in key caregiving positions use non-disclosure to assuage their own emotional burden that stems from additional challenges and responsibilities that they encounter in taking care of their loved ones.

While these narratives explicitly present situations where the patients/survivors were unaware of their diagnosis, the following section presents cases where they were aware of their diagnosis and chose to share it in varying degrees within their respective social groups.

Familial Altruism in Cases of Partial Disclosure of a Cancer Diagnosis

Sara had felt a lump in her breast and found out that she had breast cancer after a prompt medical checkup. Only her husband knew about her diagnosis, along with one sibling who lived relatively closer to her. Her other siblings did not find out until she was scheduled for surgery. Sara chose to not share the diagnosis with her mother.

Sara – I just talked to my husband. My siblings found out when I was scheduled to have surgery. Except my older brother and his wife, they knew. He is not that far away from me. That is the Indian obligation. We did not tell my mom. There is nothing she can do. My father had just passed away.

Based on Sara's statements, three factors seemed to influence the course of her communication regarding her diagnosis. There was geographical proximity coupled with the cultural obligation to share her diagnosis with her brother who stayed closer to her. Her decision to do so was guided by the fact that there was higher probability of her brother visiting her in comparison to her other siblings and his perceived hurt over not knowing what was going on with her in spite of being a close family member. However, her choice of withholding the diagnosis from her other siblings was a combination of her taking time to adjust to her diagnosis

and familial altruism as she did not want to worry her siblings. Similarly, Sara had been reluctant to share the diagnosis with her daughter.

Sara - My daughter had just started college. I did not tell her. She came to know during a video chat because I was not able to talk to her.

Lastly, the passing of Sara's father not too long before her diagnosis was a factor that influenced her decision to not share the diagnosis with her mother who was still coping with her husband's loss. When Sara's mother questioned her about her short hair upon visiting her, Sara replied "I had told her there were blisters in my hair so the doctor told me that I had to cut it". Sara's mother did not know about the cancer diagnosis until she had completed her treatment. Interestingly, it was the interpersonal dynamic between them that led to Sara sharing her cancer diagnosis with her mother. When I enquired from Sara about when did her mother eventually know, she shared that her decision to eventually let her mother know about her diagnosis resulted from a stressful phase in their relationship.

Sara - She had become demanding and had dementia. I said to her you are not the only one going through things. Everyone is going through something, and I told her about myself. She was really heartbroken.

This particular moment between Sara and her mother shows the complex underlying familial dynamic in which the disclosure of cancer unfolds. Sara's willingness to share her diagnosis had undergone gradual stages of disclosure to select siblings and finally her mother,

since she and her husband had mostly been trying to cope with her illness themselves. Similarly, in Ben's case, his daughter who had been diagnosed with cancer did not disclose her diagnosis to her children. However, her children found out about their mother's diagnosis through a class assignment.

Ben – My daughter and son-in-law did not tell their children that she had cancer. They finally told them during summer vacations. The children told me later that they were reading about cancer in school and knew all along. This happens in families. People know that someone has cancer even if that person tries to hide the information.

The disclosure of a cancer diagnosis to one's loved ones is considered to be an emotionally uphill task as part of dealing with cancer (Munro et al 2014). However, Ben's statement about the children knowing all along shows how the intended nobility behind protecting family members of patients/survivors from a cancer diagnosis can actually increase the emotional burden for them in cases where they might already sense or know about it through other sources. Similarly, the expectation of non-disclosure from a patient/survivor towards another family member can also place undue stress on that individual, such as in Nina's case. Nina was open about sharing her diagnosis with everyone as a means to spread awareness regarding seeking medical help in a timely manner. However, she had to deal with barriers when it came to managing the information about her diagnosis.

Nina – I shared with everybody. We were trying to make people aware that they should check symptoms.

When I asked Nina about experiencing any particular emotional challenges during her illness, she shared that she was not able to discuss her diagnosis with her mother since her siblings did not want her mother to know owing to old age.

Nina – I used to get depressed. I used to talk to myself. I wanted to talk to my mom. My brothers did not tell her.

Nina's situation clearly demonstrates her need for emotional support from her mother when she was diagnosed with cancer. However, her siblings were not in favor of her mother knowing about Nina's diagnosis since their mother was elderly and they considered her too fragile to handle the news. Nina's dilemma was that on one hand, she was trying to exercise her agency as a patient by making the decision to share her diagnosis and seek support from her mother. On the other hand, she was restricted by her own family members who were acting as gate keepers about who could or could not know about her illness. Although her siblings cared about her and were willing to support her emotionally through her treatment, their perceived familial altruism for their mother was having a detrimental effect on Nina. Their attitude could have possibly resulted from the presumption that since Nina's needs were already being met through treatment apart from receiving support from her spouse and other family members, it was their mother who was vulnerable and hence needed protection from the news about her daughter's cancer diagnosis. Although, these narratives demonstrate the non-disclosure of a cancer diagnosis on behalf of patients/survivors as a gesture of familial altruism, they also present instances where the patient/survivor might be in a state of conflict and duress and unable

to exercise their choice to share their diagnosis or receive emotional support due to familial intervention that is misplaced in spite of well-intentioned benevolence towards the patient/survivor.

Themes of Resilience and Agency with Regard to Disclosure

Apart from narratives of non-disclosure and partial disclosure, participants also shared their stories about being relatively open about their cancer diagnosis and the reasons the factors that influenced their decision to do so. Various participants shared sentiments of seeking support or expressing their agency by being open about their diagnosis. Another participant, Pari, shared that talking about cancer had a cathartic effect on her. She noted that, “It was good to talk about it. It should not be suppressed that much”. According to Joy and Alex, the support of their family members and friends was crucial for them during their diagnosis and treatment.

Joy - We told everyone. We actually sent emails to our friends that this is what we are going through.

Alex – Some people say I do not want to see anyone because my hair is falling. I did not hide anything from anyone. People hide I did not. I told everyone. I told the doctor I will handle it. I did not keep secrets. One of my friends did not tell her mother because she would be worried and she is old. I do not understand that. If it were me, I would want to cry in my mother’s lap. My friend did not even tell me. I got to know and I asked her. I asked her if you do not mind, I need to tell you something. I have this problem. She asked, ‘You have it?’ She was surprised.

Alex's narrative presents key insights regarding her proactive stance on sharing her diagnosis and seeking support. She was aware about cases where people might be reluctant to talk about their diagnosis but was in favor of managing her own diagnosis where she was concerned. In addition, she did not equate keeping a cancer diagnosis from a parent with protecting him/her from harm or trauma. In that sense, she did not believe in resorting to filial piety. She had a rather inclusive approach towards the disclosure of her diagnosis where she, her family members and her close friends could deal with it together. It was possibly this approach that also encouraged her to reach out to a friend who had not shared her cancer diagnosis with Alex.

Apart from using disclosure as a way to express agency, the participants' choice to both share and not share their cancer diagnosis reflected a certain degree of resilience as a means to cope with their or their loved one's illness. For instance, Simi, who had been diagnosed with breast cancer, decided to share her diagnosis on a public social media platform although her family was not keen on her decision to do so. Simi was unaware of a family history of breast cancer until she was diagnosed. She felt very strongly about being open about a cancer diagnosis, the need to communicate about it and spread awareness by sharing her own experience.

Simi – My parents said do not tell anyone. I said *main to bataongi* (I will tell). I am an adult. I am not a child. I will put on social media for education. I have many female cousins and I need to share this. I had not gone to the doctor soon enough. No one in my whole community should ever wait. I told my parents they can tell who so ever they want first if they do not want that person to find out from my social media.

When I asked Simi about the reason behind her parents' reluctance to talk about her diagnosis, she replied that her parents were concerned that she was sharing her diagnosis just to gain pity or sympathy.

My parents felt that people will think this is just to gain sympathy. That is the *desi* (Indian) way. I explained to my mom. This is not about sympathy. I want to educate people so that no one would wait this long before they see the doctor. My father is a very private man. He goes to meet others but does not want others coming to visit him if he is sick. He thinks it is about sympathy. *Abhi bhi openly sab ko nahi batate* (Even now, he does not share openly with everyone). I shared with a female relative who is American, not *desi* (Indian). After her I shared with my husband and then my parents. My heart's core was not to gain sympathy but spread education. Although, there was outpouring of sympathy but that is okay.

As mentioned earlier, Simi had mistaken a lump for a cyst and had waited a few months before making an appointment with a doctor. Her statement regarding sharing the diagnosis first with a relative who was not Indian before sharing it with her family shows her intention to seek reassurance and support from a source where she perceived the topic of cancer to be more approachable than in her own family. In addition, Simi's statement about, "that is the *desi* (Indian) way" and relating it to being prideful, not wanting sympathy or pity and viewing privacy as a representation of stoic suffering places her experience of disclosure between two contrasting viewpoints of defiance towards pity through non-disclosure and defiance towards parental authority through disclosure of a cancer diagnosis. Simi's intention to use her story as an

example for improved cancer communication and awareness reflects a form of altruism and agency from the patient which is in contrast with the benevolent altruism shown by family members through non-disclosure of a cancer diagnosis.

In addition to negotiating disclosure of their health status, patients/survivors exercise agency at different stages of their illness. Nita had been caring for her father during his treatment for cancer. She had chosen to not disclose his diagnosis to him since he was elderly. When I asked Nita if she thought he knew at some point, she shared that her father had expressed his decision to not receive further treatment once he knew that he had cancer.

Nita – I think he knew eventually because once he told me that he knew and that he was okay. He never used to tell us what he was going through. He also said that he does not need the treatment anymore.

Nita's statement about her father not discussing his thoughts or feelings could result from the fact that patients who do not receive a formal disclosure of their diagnosis may not feel that they are in a position to share their experience with the illness. Other participants who knew about their diagnosis also shared similar sentiments. These participants were reserved about sharing it with other people outside their immediate family.

Anita – I did not discuss because I did not want to cut a sorry figure.

Sara – I am strong enough. I purposely did not tell my friends.

Eva – I do not know what his mentality was, he was very positive.

These vignettes and particularly Eva's remark about not really knowing about her husband's thoughts but seeing him display a positive attitude show that non-disclosure often fosters an environment of "do not ask, do not tell," which further perpetuates the archetype of the quietly suffering stoic patient. Therefore, silence is often construed as a symbol of strength and resolve and talking about the illness is equated with excessive vulnerability or being the subject of pity.

Factors that Impact Decisions Regarding Disclosure

Based on participant narratives, there were key factors that influenced participants' decision regarding the disclosure of a cancer diagnosis. Apart from discussing the patterns of cancer disclosure, this study highlights the different factors that influence cancer disclosure and communication in the Indian community. I have outlined these factors based on recurring themes in participant narratives.

Positioning, Family Hierarchy and Cancer Disclosure

Tina – I had back pain. I went to the doctor and the doctor said that I might have an infection. I made an appointment with a relative who was a doctor. She came to visit me at my place. She took my mom inside the room. They did not tell me anything. They both came out of the room and they were crying. I was calmer than anybody else. Everyone made it seem like I am dying or something. It's more about privacy here. She was in the

room with my mom. I was not even there. People have died of cancer because they never sought treatment and came to know too late. My aunt made it seem like it was really bad than it was. The doctor here said let's do this and then we will talk about surgery. It didn't seem that bad here. Back in the day people were scared of cancer. It seems weird but I think there is still not enough education. The mindset is it is cancer. You are going to die.

Tina's case presents an interesting and insightful narrative about cancer disclosure. Tina was not the first person to know about her diagnosis in spite of independently seeking consultation about her symptoms from her aunt who was a physician. Her aunt, on diagnosing that it was cancer, chose to share it with Tina's mother while Tina was also present there. Tina's statement about her aunt and her mother being in a separate room show how Tina was excluded from the conversation about her diagnosis even though was neither an elderly person nor someone who had a language barrier in understanding English. Hence, she did not fit the stereotype of individuals who typically might not have access to their diagnosis based on other participant narratives. Yet, the shock and fear that Tina's mother and aunt felt on knowing her diagnosis was so intense, that they circumvented her right to be included in the conversation in a bid to protect her from knowing the diagnosis right away, and as an attempt to come to terms with the diagnosis while she was there. This represents medical authority coupled with familial altruism in a social space that was beyond the site of the clinic.

Similarly, Kiran's father was diagnosed with cancer in India. Her family chose not to share his diagnosis with her father or with her initially. She eventually came to know when she

visited her father. Even her father was not the first person to know about his own diagnosis since the doctor had shared the diagnosis with Kiran's brother.

Kiran – They did not tell me for a long time. They told me that he was operated upon for stomach infection and I came to know 6-7 months after his surgery. My brother finally told me.

Kiran was one of the younger siblings and was residing in the United States when her father was diagnosed with cancer. Her older brother was handling the clinical appointments and treatment and hence was also the key decision maker regarding how any of the information pertaining to their father's illness was handled. As obvious from Kiran's statement, she did not know about her father's diagnosis until a few months into her father's surgery. Her father did not know formally about his diagnosis. Although familial altruism was at play in Kiran and her father not knowing about the diagnosis, it was also geographical proximity and her positioning as a younger female sibling that determined her access to the information regarding her father's diagnosis. Similarly, Priya's grandmother had been diagnosed with cancer and both Priya and her grandmother were unaware of it.

Priya – I was not told for a long time. My uncle was a doctor. He was in favor of telling her. I and some of my family members did not want her to know. I think she got to know towards the end.

Priya shared that her grandmother's children including her mother were split about informing her grandmother of her diagnosis or not. One of her uncles who was a physician was in favor of disclosing the diagnosis to her grandmother while Priya and a few other family members were opposed to that proposition. According to Priya, the cancer was in an advanced stage and it did not seem reasonable to disclose the information about the diagnosis since there was a very slim chance of her grandmother surviving the cancer. Unlike Kiran and Priya, Bela and her husband were in India when her brother-in-law was diagnosed with cancer. Bela's husband and brother-in-law were siblings and had shared a close bond since childhood. Yet, her husband was one of the last people to know about his brother's diagnosis.

Bela – They took him to the hospital and it was written 'Cancer Department.' He asked why you have brought me here? Then the doctor told it is third stage. Nothing can happen now. We only knew one month before his death. His sons came to know first. We did not share his diagnosis with anyone because in India, people don't share or tell each other. Everyone just kept hearing that "*bimar hain, bimar hain*" (is sick, is sick). All his other relatives and siblings knew only when they came to visit him.

The prognosis for Bela's brother-in-law was poor as the cancer had reached an advanced stage. Bela shared that all that she would hear from her brother-in-law's family is that he is just sick without mentioning the diagnosis of cancer. His sons knew about the diagnosis but had withheld the diagnosis from him, his siblings, and extended family members. They and their wives were the primary caregivers and were also shouldering the cost of the treatment. Their

positioning with regard to being his sons and making decisions regarding his treatment granted them access and authority that even his own siblings did not have in the matter.

The above conversations illustrate the positionality of the participants with regard to disclosure of the diagnosis. Kiran, Priya, Bela and Charu's cases demonstrate secrecy and restraint regarding the cancer diagnosis. However, their positions differed with regard to place and hierarchy in the family. Kiran was not in India when her father was diagnosed with cancer. Hence, her absence could have played a part in her not knowing about her father's diagnosis. Similarly, Bela and Priya did not have a direct say in whether their family members should know about their diagnosis since the children were the key caregivers and decision makers in both cases. On the other hand, Charu had better access to her husband's medical information as a spouse and as a family member who was present for the interactions between herself and the provider. In addition, she undertook the responsibility of conveying the information directly to her husband. Kiran and Charu's cases highlight their perception of a patient's reaction regarding diagnosis in case of a malignant illness such as cancer. It shows that the ethic and the practice of withholding information from a family member is synonymous with protecting them from trauma. The following statement from Charu reaffirms this finding: "I wanted him to be himself and have a life as normal as possible."

However, withholding a patient's medical diagnosis in case of cancer is also related to the shift in patient's perception of himself/herself upon receiving the information. According to Kiran, her family did not share the diagnosis with her father so that he would not develop feelings of self-pity. Charu echoed a similar sentiment by sharing that she was concerned that her husband could have encountered difficulty in coping with his illness given his personality: "I did not want pity for him or for myself." Hence, various participants expressed their feelings of not

wanting to be seen as a subject of pity, which was synchronous with feelings of self-respect and pride. Because cancer is viewed as an immensely difficult illness to deal with given its effect on the physical body, and increased emotional and financial strain, some of the participants often used restraint as a tool of resistance to deal with the illness and the fear associated with it.

Age

Many participants considered age as a factor in the decision to discuss a cancer diagnosis with patients or family members. Indian culture in general places a lot of value on filial piety, which includes preserving family relationships and service towards parents and community elders as a way to ensure their well-being in old age (Awasthi and Awasthi 2017). Traditionally, younger individuals within a family unit are expected to provide support and care for the elderly. In addition, Indian government does not have a public federal program such as social security (Lamb 2002). Also, India does not have a universal system for covering health care costs for a large majority of its elderly population (Ahlin 2017). Hence, the traditional obligation to care for the elderly as part of fulfilling one's filial responsibilities often drives the ethic to protect them from any kind of physical and emotional harm. A diagnosis of cancer is believed to pose that risk for the elderly and hence, an individual's age often influences the communication regarding a cancer diagnosis. As participant mentioned, an elderly individual who is suffering a poor prognosis of cancer need not know about his/her diagnosis.

Priya - They should not know. If it is not curable, and the age is too much, they should not know.

Priya firmly believed that advanced age and the severity of cancer were justifiable reasons for the non-disclosure of a cancer diagnosis. Similarly, even though Joy had shared earlier that she and her husband had sent e-mails to their friends and family regarding her diagnosis of cancer, she did consider age as an influential factor in having a patient know about their diagnosis. She shared that her own father in law had not known about his diagnosis because he was elderly. She considered cancer disclosure to be circumstantial and variable on a case by case basis.

Nita – If he was younger, I probably would have told him but then he would not have told us. Cancer is scary in itself. I don't know.

Kiran – A person should be told even if the person is old. What is the use of hiding? It really does not change anything.

While Priya, Joy and Nita agreed that withholding a cancer diagnosis from an elderly person was an act of benevolence, particularly in cases of terminal cancer, Nita felt that her father would not have shared his diagnosis if he was younger, and had he known about it. This comment denotes Nita's approach towards cancer disclosure and familial altruism as practices that exist mutually between the patient and the family member. According to her, both patient and family member might not communicate with each other regarding a cancer diagnosis based on age and who gets to know about it first. Hence, non-disclosure can be a mutual act of kindness or as a way to reject perceived pity. On the other hand, Kiran felt that patients should know about their cancer diagnosis irrespective of age. When I enquired from Kiran about

whether she felt that her father should have known, she answered in the affirmative. She felt that concealing a cancer diagnosis from a patient is futile regardless of the patient's age since concealing a cancer diagnosis does not resolve the illness. She believed that it did not lend any benefit to the patient in the long term, and open communication among patients and family members was a better way to deal with a cancer diagnosis and illness.

These vignettes illustrate that age, especially in case of the elderly, becomes a determining factor for the non-disclosure of a cancer diagnosis. Filial piety and values of service and care for the elderly occupy high regard in traditional Indian culture (Awasthi and Awasthi 2017). However, to withhold the diagnosis on the basis of fragility associated with age also counteracts with the agency of the elderly as individuals who reserve the right to know about their illness and may want to take autonomous decisions regarding treatment or other key issues such as end of life decisions. For instance, Nita's father demonstrated agency when he told her that he knew that he had cancer and did not want to continue further treatment. Hence, even though participants cited being elderly as one of the primary reasons for not disclosing a cancer diagnosis, it has ethical implications with regard to the autonomy of the patient that they may feel they have the right to exercise. However, this also becomes a ground for conflict for family members who already feel weighed down by caregiving responsibilities for the patient and consider dealing with their perceived anxiety of knowing about the diagnosis as an additional emotional burden to cope with such as in Kate's case.

Support as a Factor in Disclosure

Apart from age and familial hierarchy, the need to receive or deny support was an instrumental factor in the disclosure of a cancer diagnosis. The participants varied in their

reasons for seeking or not seeking support and its effect on the extent of their communication regarding their cancer diagnosis.

Kate was the primary caregiver for both her parents who were suffering from cancer. She talked about the difference between how her father and mother had approached the disclosure of their diagnosis in wider social circles. While her mother was open towards sharing her diagnosis with other people, her father was hesitant to talk about his diagnosis due to side effects from radiation and as a way to avoid pitiful reactions.

Kate – My dad was a little hesitant. His skin had burned because of radiation. He did not want to talk to anyone. He did not want sympathy. Mom is okay. She wants empathy.

Kate's parents had a different approach towards talking about their diagnosis. Kate's father's case shows that physical changes in appearance due to treatment can affect a patient's ability to talk about their diagnosis. Also, his feelings regarding not wanting sympathy were synonymous with several other participants who viewed it as a devaluation of their self-worth. Cancer patients have often reported psychosocial issues of struggling with a negative body image and low self-esteem (Ganzer et al 2015) as evident with Kate's father. In contrast, Kate felt that her mother was open about talking about her cancer because she was seeking empathy to cope with her cancer diagnosis. Similar to Kate, Nina, and Alex felt that talking about cancer mitigated their anxiety and provided an outlet to deal with the stress of the illness.

Nina – You do go through things when you are sitting alone, and you get worried. It is good to know everything and discuss with everybody.

As opposed to some of the other participants such as Sara, Alex was not in favor of concealing the diagnosis from an elderly parent due to their age. She felt that it was important to garner any amount of available emotional support during an illness that was as grave as cancer. In contrast, Amy felt that talking to everyone about her diagnosis was an infringement on her privacy and an impediment to the process of healing. She shared that she was in a position to afford domestic help and did not want to feel smothered by expressions of concern during her treatment.

Amy – I did not want to talk too much about it because you know, people become pests. They are like, what food should I send?

On the other hand, Eva shared that she went through a mixed phase of withdrawal and the urge to talk about her husband's diagnosis. Apart from giving herself time to accept the situation and feeling defiant towards sympathetic reactions, she also felt that talking about the diagnosis compounded her fear and concern regarding her husband's illness due to hearing different viewpoints which were not always positive.

Eva – You don't feel like mentioning to everyone what you are going through. For one month, I couldn't mention anything to anybody. We don't want anybody's sympathy and sometimes, people scare us. We decided we will handle it by ourselves.

However, Eva shared that she also felt resentful towards some of her friends who did not proactively offer help once they came to know about her husband's diagnosis which sent her into a phase of emotional withdrawal.

Eva - No one understands that we want support. They think we want privacy. I did not really want to talk to relatives because we were exhausted and no one can come to help.

Eva's narrative shows the variable range of emotions that patients and family members undergo during a diagnosis of cancer. The shock of dealing with the diagnosis, subsequent cycle of medical consultations, and side effects of treatment often has an intense physical and emotional impact on both patients and caregivers which influences interpersonal communication regarding cancer in variable ways that range from emotional withdrawal to seeking uninhibited forms of support. In addition, participants' reasons for being open about their disclosure depended upon how the participants felt about specific circumstances in their life. For example, Cindy shared that she did not see a reason to hide her diagnosis of cancer. "We were very open. The kids are happy and happily married". She further shared that her husband and herself had already completed their parental responsibilities of providing their children with an education and helping them to be financially independent when she was diagnosed with cancer. Hence, she did not have to worry about anything else and had to only deal with the cancer. Two other participants Mona and Joy felt that being educated or having a medical background helped to be open about talking about a cancer diagnosis.

Mona – We always openly discussed about the cases of cancer in our family. We have a medical family background.

Joy – Everyone is educated. It was discussed with family members and outside.

Although Mona and Joy emphasized that the level of education influenced the willingness to openly talk about a cancer diagnosis, this did not apply to other participants who had a college education and showed that educational background did not uniformly influence disclosure of a cancer diagnosis. Sentiments of familial benevolence and altruism along with age and support had a stronger hold on how participants approached the disclosure of a cancer diagnosis. For instance, the urge to protect the patient overruled the level of education in families with highly educated backgrounds such as in the case of Charu and Priya while age factored into the decision about non-disclosure in Kate, Nita, and Leela's cases. Similarly, the need to seek social support or maintain privacy was evident in Anita, Eva, and Alex's cases.

While there has been considerable emphasis on the role of social support in healing, this might not be true in all cases. Some participants considered social support to deter their process of healing because they perceived it as undue attention since they already had emotional and functional support from family members or had sufficient financial resources to hire domestic help in certain cases. For others, the experience of dealing with cancer and its treatment was an internal and private process, and hence they did not foresee the need for external social support. Finally, in certain cases, individuals considered the experience of cancer to be an opportunity for personal and spiritual growth and viewed the need to socialize as a superficial outlet that they had indulged in previously. These findings show that while social support can be vital to the

process of coping with cancer, certain individuals may be reserved about seeking or accepting it due to issues of privacy, side effects of treatment and as a way to exercise self-reliance. In addition, the participant narratives illustrate that the experience of dealing with cancer illness is highly individualistic for participants depending upon the type and stage of cancer.

Cancer Beliefs, Metaphors and Disclosure

During the interviews, I explored participants' perception of cancer as a way to enhance my understanding of their responses toward cancer disclosure and communication. According to Chittem et al (2013), there is limited data on patients' beliefs about cancer related illness which can provide a crucial perspective on the ways in which individuals react to a health condition. Susan Sontag has extensively written about the overlap in comparisons between cancer and tuberculosis in her seminal essay "Illness as Metaphor" (1978). According to Sontag, cancer is often referred to as an "invasion" within the body while tuberculosis is referred to as the "consumption" of the body among various metaphors that have been assigned to these diseases. However, in this section, the participants use metaphors to convey their understanding of cancer as a disease and as an illness.

Additionally, the Common Sense Model posits that individuals form their impression and response based on lay perceptions about the disease when faced with a serious illness (Chittem et al 2013). Hence, participants' views about cancer and the metaphors that they associated with it were instrumental in providing an in-depth insight into the reasons for intense and varied reactions towards disclosure of cancer. The participants were asked to compare cancer to an animate or inanimate object to gain an insight into their notions of cancer and the impact of illness among them. Majority of the participants presented metaphors that corresponded with

negative images of cancer that demonstrated an immense fear of cancer. At the same time, the participants also presented metaphors that reflected their agency concerning their experiences of cancer.

Metaphors

The participants were asked what cancer would be if they could imagine it as an object or a life form. Given the possibility that this question could be unconventional or puzzling for some participants, I gave examples of ordinary, inanimate objects to avoid influencing their responses. For instance, I chose to mention a table or a chair as examples just to clarify that the participants need to relate their response to a physical object or animal. However, I refrained from using examples with a negative association because I wanted their response to be organic.

According to Kiran, cancer was like a cactus with thorns that can never give any comfort. She shared that she lived with her father's illness and death every passing day.

Kiran - It is like a cactus with thorns that pricks even on touching. That is the first thing that came in my mind. Something that can never give comfort. I live with it every day. I wish no one had it.

Kiran's response showed strong feelings about cancer and the impact of her father's illness and loss on her psyche. Charu compared cancer to a snake which could cause harm depending on the stage of cancer at diagnosis.

Charu - It is like a snake. It is poisonous or non-poisonous depending on stage. If it is stage 4, it is poisonous. If it is at an early stage, it is not poisonous. It can scare me but it would not bite me.

Charu's response showed a certain degree of control that she can have on cancer as an illness depending upon the stage of the disease. Tina equated cancer to a bug that one could get rid of with timely and appropriate treatment.

Tina - Cancer is like a bug really that you can squish and get rid of it. I can look at it that way but not everyone can look at it that way.

Tina's analogy stemmed from her experience as a cancer survivor where she felt relatively in more control after having completed treatment. Hence, the participants' responses demonstrated different reactions even though they associated cancer with largely negative images which reflect their experiences and attitudes regarding cancer. Kiran considered cancer to be a source of discomfort and pain given her memories of watching her father suffer and her grief over his loss. In this regard, she felt that she had to cope with the grief since she could not do anything about her father's illness. For Charu, the extent of harm from cancer was dependent on the severity, demonstrating a certain amount of objectivity in relation to seeing her husband and her relatives go through various stages of cancer illness. In contrast, Priya felt too affected by her grandmother's illness and loss. She felt that she was unable to imagine cancer in a material form because she did not like to think about it. The only way for her to deal with her grandmother's illness and loss was by escaping from any thoughts of cancer.

Priya - I cannot relate it to anything. I just do not want to think about it. This is my way of escaping from it.

Other participants mostly equated cancer to a poison that “keeps eating you”, “a killer disease”, “a definite threat,” and “a slow poison that is definitely a threat”. One of the participants, Nita, stated that cancer was a poison for people who had lost their loved ones.

Nita – There are so many survivors as well as ones who have lost their life. It is certainly poison for them.

Daisy – Cancer is like something sticky, like slime that you cannot get off. It just stuck to different parts of his body and you cannot get it off.

Nick – It is something that slowly eats you. It was with him for a long time and it was killing him. By the time you know, it is too late. We did not get a chance to fight back. That is the scariest part. I know it is not hereditary but every time I feel pain in the back or feel sick, I think if its cancer though I know it is not the case.

Nick’s statement illustrates the psychological impact of experiencing a family member’s illness concerning cancer. Nick’s father had passed away due to cancer within a few months of his diagnosis since it was diagnosed in an advanced stage. Hence, Nick’s feelings about his

father's illness show paranoia anytime he felt any body pain and a feeling of helplessness towards cancer as something that was initially invisible but damaging to his father's health.

Apart from Nick, Daisy equated cancer to slime as she had lost a close relative to cancer. Joy compared cancer to a form of flu that she feared could come back any time except that it was more severe than flu. Although, Joy's fear regarding recurrence of cancer has been reported by cancer survivors in other studies, (Crist et. al 2013) Nick's concern demonstrates that even family members experience post-traumatic stress related to a loved one's illness and loss and can often feel paranoid regarding their own health. Interestingly, survivors described cancer in ways that spoke of agency and a certain degree of control over the illness while family members who had lost loved ones to cancer tended to equate cancer with relatively negative metaphors. Thus, the participants' reactions posited a connection between their experiences and perceptions of cancer highlighting contrasting feelings of distress, control and agency.

Beliefs on Causation

In addition, the participants shared their thoughts on the cause of cancer. The reason behind exploring participants' reasons for getting cancer were a way to gauge their perception of cancer and whether it influenced their communication regarding cancer. The participants attributed the development of cancer to mostly stress although some of the participants also emphasized the role of diet and environmental pollution.

Alex – I was like I have no bad habits. I eat simple vegetarian food. No drinking or smoking. Why did this happen to me? My parents and in laws never had meat. Not even eggs. Maybe it was in my *kismet* (destiny). I had taken a medicine. I had seen its ad on

TV. All ladies were taking it to deal with menopause. They then made ladies stop taking that medicine. I asked my doctor if the medicine could have caused the cancer. He said no. He said everyone has cancer cells. It is just who gets exposed to them.

Alex's statement shows that she felt very baffled with her diagnosis and was attempting to rationalize it based on either diet or hormonal replacement therapy to deal with symptoms of menopause. Similarly, Anil emphasized the role of individual behaviors over genetic markers in his brother's case who had passed away due to cancer.

Anil – I do not think it is genetic. It was his lifestyle. He smoked, he drank. I stopped smoking 20 years ago.

On the other hand, Kiran considered environmental pollution as a risk factor for cancer although she also believed in incorporating an organic food based diet.

Kiran - One needs to go all organic and not use plastic. Cancer is man-made. It is not natural. It is the mutation of cells. The causes are environmental too. Pollution was a factor for my dad. His work was in the most polluted area. There was industrial pollution.

Apart from suggesting occupational health as a concern, Kiran also attributed her father's discord with one of the family members and financial losses to his diagnosis of cancer. She also expressed that negative human emotions such as stress and anger were responsible to an extent in causing cancer.

Kiran - We need to live a stress-free life and not have negative thoughts. Stress was actually one of the causes for my dad. The business split and my dad was in debt. Our own emotions such as anger, insecurity and stress cause cancer too.

John – We get asked if eating chicken caused this but there is no scientific proof. They say you eat turmeric, you will not get cancer. Nobody has proven so far, which will cause what but there might be some association. Patients may initially blame themselves but they get over it.

In contrast, Charu shared that she never gave much thought to the reasons behind her husband developing cancer though she also acknowledged the relevance of stress in developing cancer.

Charu - I never thought about what caused it. Maybe, a person's negativity and having anger inside can cause it. Stress can really change your genes.

Similarly, Sara also attributed stress to the cause of her having a diagnosis of cancer. She shared how she was deeply affected by every issue in her family and usually kept her emotions to herself which she thought played a role in her diagnosis of cancer.

Sara - Initially I was not sharing my diagnosis with everyone. I was only talking to my husband and not my siblings. I would also internalize every problem in the family. I

thought that is why this happened to me. I used to keep things with myself. Then I felt I should be sharing this with somebody other than my husband.

The above narratives show that nearly all participants considered stress to be a major factor in the development of cancer in addition to associating feelings of anger and interpersonal discord with negative thoughts that can cause illness. In addition, participants listed environmental pollution, genetic history and a diet laden with processed or inorganic foods as some of the causes of cancer. A section of the participants did not associate cancer with any cause and considered it as an event that just happened. They shared that they did not have a family history of cancer and did not associate it with anything other than the physiological changes in their body.

Amy – There was no known cause. If I had a stroke or a heart attack, then I could say that it happened because I was obese or fat.

Amy's statement provides an insight into how individuals rationalize illness depending upon the type and stage of cancer. Similarly, Ray, who is a health care provider, also compared heart disease with cancer and felt that it was the lack of awareness and the general fear regarding cancer that led to its perception of a dreaded illness.

Ray – Some diseases kill the patient right away. Heart attack is a lot worse than cancer. They don't die right away. But people are more dreadful about cancer because they are

not educated about cancer. They are born in 50s and 60s. Treatments were not there at the time. Even Americans think that it is dreadful.

Gathering from Ray and Amy's statements, I found the incidental comparison between cancer and heart disease noteworthy. These narratives seemingly suggested that although there are a host of medical disorders associated with the heart, heart disease in general is mostly affiliated with cases of heart attack and heart failure as opposed to cancer that can manifest through multiple channels in the body.

Additionally, Sontag highlights that heart disease is primarily viewed as a "mechanical weakness or failure" whereas cancer is often associated with an awful existence (Sontag 1978). Although, cancer is classified as a cluster of diseases (American Cancer Society 2019) with various types of cancers having different etiological pathways, genetic markers, symptoms and treatment plans, the origin of cancer is not limited to any one particular site in the body. In contrast, the heart is virtually seen as the locus of cardiac related issues and its afflictions can be pinned down to one area of the body and specific causes such as obesity unlike cancer which the participants felt appeared out of nowhere in spite of lack of family history and/or dietary and behavioral choices that the participants associated with the development of cancer. In addition, participants' association of various factors such as stress, anger, negative thoughts, diet and environment assigned cancer a certain "suddenness" and ambiguity in terms of its occurrence which further intensified the fear of getting cancer.

Overall, the participant narratives show that a range of complex factors such as socio-economic background, age, interpersonal relationships, role and position within the family, cancer-related beliefs and perceptions and prognosis of the disease influence the communication

involving cancer disclosure and decision making among individuals and families which warrants a close examination and consideration of these components in shaping the discourse on cancer communication, individual agency, illness experiences and family histories of cancer.

Discussion and Theoretical Reflections

Facets of Disclosure

Besides India, the non-disclosure of a cancer diagnosis is known to exist in several countries such as Japan, China, Singapore, Spain, Greece, Sweden and Italy (Ni and Alraek 2017). The non-disclosure of a cancer diagnosis to the patient has been documented in select countries where family members often assume key positions as caregivers and decision makers (Chittem et al 2013). Although the existing literature acknowledges the types of disclosure that occur with regard to cancer communication considering familial influence and collective decision making in select social groups, the participant narratives highlight the various facets of cancer disclosure and how they operate across multiple social ties and groups. For example, Simi's case presents an instance where she did not share her symptoms with anyone for a certain length of time, being oblivious to her own family history of cancer and partly due to denial which exacerbated her illness. On the other hand, Sara, Anita, Kate, and Amy's cases illustrate situations where participants were reserved about sharing their diagnosis with other family members and/or wider social circles.

I have categorized these cases under partial and full disclosure although the literature frames partial disclosure and full disclosure as situations where patients choose to receive limited information or complete information about their cancer diagnosis. The reason for taking this liberty was to look at cancer disclosure from the perspective of all parties which include

patients/survivors, family members and health providers, especially since cancer has a long term impact on an individual's health and interpersonal relationships. In doing so, my objective has been to articulate and understand cancer disclosure and present the lived experiences of cancer in the Indian community.

Another key theme that has emerged in participants' narratives is the sentiment of resilience, which unfolded in distinct ways in cases of full, partial and non-disclosure. However, Kitanaka argues that resilience as a concept has also been applied in non-military contexts among individuals to recover from trauma with the assistance of therapeutic technologies and lead a presumably healthy life (2015). Scheper-Hughes identifies "tactics of resilience" where she states that "strength, emotional control, courage, and self-sufficiency along with a display of invulnerability to pain and suffering are moral virtues that are rooted in rationality, principled behavior, dignity and duty" (2008). These characteristics were embodied by participants in varying degrees, especially when it came to withholding emotional expressions of vulnerability or fear in front of spouses, parents, children or wider social circles in cases of partial and non-disclosure.

In contrast, in cases of full disclosure, resilience implied that participants were willing to share their diagnosis with everyone to accumulate support and as a gesture of defiance against any secrecy associated with a cancer diagnosis. Thus, participants exercised self-reliance as a coping mechanism in their decision to both withhold and disclose the cancer diagnosis. However, self-reliance itself could manifest in diverse ways where participants either chose to talk about their illness or were stoically quiet about their feelings. The reasons for choosing not to share diagnosis often included not wanting sympathy, intrusion of privacy, or wanting to handle the illness on their own. On the other hand, the decision to disclose a cancer diagnosis

was a way to defy the secrecy associated with a cancer diagnosis and hence became an act of resilience towards either familial authority such as in Simi's case or the norms that normalized concealing a cancer diagnosis as was obvious in Joy and Alex's cases.

Cancer Disclosure and Therapeutic Management

Additionally, participant narratives show that families often act as gatekeepers between patients and providers and patients and the wider social circles regarding the disclosure of a cancer diagnosis and decisions regarding subsequent treatment. These findings align with the literature on therapeutic management, where health providers and family members collectively form an essential component of therapeutic management for individuals diagnosed with cancer (Janzen 1987; Bossart 2003, Chittem et. al 2013). One of the factors that primarily account for this dynamic is that the health providers in India are generally attuned with the position of the family in accessing critical health information and participating in crucial health related decisions concerning the patient (Chaturvedi et al 2014). The participant narratives show that many participants who were caregiving family members often operated from this position of familial authority, leading them to intervene and control health-related information that was being disseminated around the patient. In this regard, the participants who were family members negotiated and challenged medical authority and the conventional roles of the health provider and the patient as two predominant participating members in decision making.

Thus, the site of the clinic often became a negotiation ground for disclosure of a cancer status among family members and health professionals where socio-cultural sensibilities often infiltrated the seemingly socially sterile clinical space supposedly bereft of such influences. These findings illustrate that the presumed objectivity of the biomedical infrastructure is more

often than not diluted with cultural norms associated with an illness. These findings underscore the prominence that Kleinman (1998, 2013) places on the social context of the lives and histories of patients and the myriad ways in which they experience and contextualize an illness as opposed to looking at the practice of medicine as an operative instrument of bio technology.

Familial Altruism as a Mutual and Multi-dimensional Strategy

The participants' narratives show that familial altruism is multifaceted and two-sided, where patients demonstrate their protectiveness towards close family members through expressions of stoicism and resilience. Withholding expressions of fear, concern, and discomfort during the diagnosis and illness are ways through which patients/survivors have demonstrated their protectiveness towards close family members, especially their children and elderly parents. The most common reasons that participants reported included creating any distraction towards their children's' education and careers or causing trauma to elderly parents. In addition, the caregiving family members frequently acted as gatekeepers towards the patients/survivors which was in accordance with the literature on cancer disclosure (Gregg 2003; Good et. al 1990).

However, participants also reported instances where familial altruism was overbearing and stressful, particularly in Nina, Kate, and Tina's cases. While Nina and Kate underwent immense stress in caring for their sick parents, Tina felt excluded from the right of knowing her diagnosis in her family's presence although the primary intention was to protect the ailing individuals from emotional despair in all of these cases and the non-disclosure of a cancer diagnosis was viewed as a form of familial/illness altruism on behalf of participants who either made that choice towards their loved ones who had been diagnosed or considered it as a

justifiable option in selective cases based on the age of the patient or the stage and prognosis of cancer.

For instance, terminal illness and the inevitability of dying seemingly served as a justification for non-disclosure of a cancer diagnosis in cases where the prognosis indicated slim chances of recovering from the illness. In such situations, the participants seemed to be so overwhelmed by the emotion of wanting to shield their loved ones themselves, the non-disclosure of the diagnosis became an act that was more morally justifiable than not doing so. In addition, the non-disclosure was also treated as a gauze for coming to terms with the reality of the diagnosis themselves. In these situations, the participants did not have to consider dealing with the consequences of not sharing the diagnosis with their terminally ill family members since death was a predetermined outcome of the illness. Hence, the sentiment of protectiveness or altruism associated with not sharing a cancer diagnosis superseded the moral conundrum of not disclosing the diagnosis to the patient.

Although I have provided participant narratives that reflect partial and non-disclosure of a cancer diagnosis, my intention is to not present these accounts as the dominant representation of how cancer communication occurs in the community. My objective here is to illustrate that disclosure of a cancer diagnosis is a multifaceted phenomenon where family members may play an important role in the communication and treatment of cancer in the Indian community. Through this study, I argue that disclosure of a cancer diagnosis and subsequent information concerning prognosis and treatment is a multifaceted and a multidimensional process.

In addition, the existing literature primarily frames cancer disclosure around the conversation between a patient and provider. While this framing provides key insights into how patients and families approach cancer disclosure, it predominantly situates cancer disclosure in

the clinical domain. The participant narratives in this study illustrate that cancer disclosure occurs across various social channels and actors where clinical interaction is only one component of how cancer is understood, lived and articulated as an illness. Hence, cancer disclosure and communication needs to be understood beyond a “yes” or “no” response for patients and family members. It often exists on a continuum and is constantly shaped and negotiated among several stakeholders based on cultural sensibilities and interpersonal relationships.

CHAPTER FIVE:

CANCER, SELFHOOD AND CAREGIVING

“Cancer does not happen to just one person. It happens to the whole family” - Claire

This chapter discusses experiences of caregiving among cancer survivors and their family members. In addition, it presents insights on the various forms of support that participants received as patients/survivors and provided as caregivers, and its impact on their lived experiences of cancer illness. During the interviews, participants discussed the changes that occurred in household and professional responsibilities as a result of being diagnosed with cancer. Participants who were employed at the time of diagnosis had to make adjustments to their employment schedules or leave their jobs altogether. Apart from survivors, family members also had to reorient their social and professional lives around caregiving responsibilities for their loved ones. This section highlights the collective impact of a cancer diagnosis and treatment on the orientation of gender and familial roles and social and professional obligations among survivors and caregiving family members. In addition, it highlights the emotional and mental impact of a cancer diagnosis and how individuals define their selves and their agency through the experience of cancer.

Division of Labor during Cancer Diagnosis and Treatment

The following narratives present cases where participants were employed full-time or part-time during treatment, fulfilling their professional and domestic responsibilities at the same time, and how it relates to the literature on gender roles. These cases also present the different types of support that the participants received from family members and friends to help them through treatment.

Alex shared that she had two jobs when she was diagnosed with cancer. She resigned from one of the jobs post-diagnosis.

Alex – I was working part time when kids were small and then I went full time. I was working 60-70 hours before falling sick. I left my second job once I was sick. I saw that so many women were working and doing chemo. Some women left work and stayed home for a year. I was like I have to work because I am not at retirement.

As Alex's case shows, she had a strong motivation to retain her employment due to seeing other women undergo a similar experience of working while undergoing treatment for cancer. In addition, Alex had been working outside of home early on and felt obligated to work since she was not close to retirement. She also shared that work served as a distraction from cancer during the course of the interview. Alex's case relates to many Indian immigrant women who feel obligated to and are expected to contribute financially post-immigration. Additionally, starting life from scratch often requires women to be both caregivers and co-providers, which increases their overall workload related stress in the United States (Rangaswamy 2000). With

regard to the change in household responsibilities during treatment, participants had varying experiences. Some participants shared that there had always been a shared workload of domestic responsibilities, while others reported that they began receiving increased assistance from spouses and children post-diagnosis and during treatment. Alex noted that her husband had always helped her with completing household tasks and his assistance only increased during her illness.

Alex - I am like a house lady. Work is work. House stuff is house stuff. My husband would come in the evening, take some rest and clean and cook. Sometimes, we would get food from outside. After surgery, I would clean and cook a little bit. I would make roti and my husband and children would make other dishes and tea. They would also do the laundry. My husband has helped me from the beginning but it increased for him after I fell sick.

Similarly, Anita shared that she and her husband had an egalitarian approach towards sharing domestic tasks throughout their marriage, although she felt that Indian women usually dealt with an increased share of household responsibilities even if they received assistance from their spouses. She felt that a relatively equal division of labor between her and her husband had more to do with the specific circumstances that applied to their lives in general. Both she and her husband were highly educated and employed in demanding jobs which required them to equally share household obligations. Additionally, Anita did not have young children to care for since she was diagnosed with cancer at a later stage in life and hence did not have to deal with

caregiving responsibilities. Anita shared that the one area where her husband and her had to switch roles was that of household finances since she had been primarily handling the family's finances prior to her diagnosis and had to delegate that task to her husband during her treatment and recovery.

Anita – You know that generally women share quite a bit of household responsibilities. We were not a run-of-the-mill family. There were no small kids. Our kids were grown up and settled. My husband eats one meal a day, a healthy meal which was provided to him. I had only had a few years left for retirement so we were already at that phase of life. I went through a phase of taking care of finances. It was 80-20. Then the share became more on him but there is online banking. It is convenient now. I also had a lot of help. I had my sister's help, house help and emotional support from my family.

While Alex and Anita shared that there was a fair division of labor regarding domestic chores between spouses in their respective households even before the diagnosis of cancer, a few other participant admitted that that was not the case. Cindy shared that the division of labor at her home had been fairly stereotypical with her shouldering most of domestic responsibilities though her husband provided her with ample emotional support during her illness. She admitted that she received immense help from her friends, even though she was not expecting it at the time.

Cindy – Typical Indian husbands don't do that much. My husband and children supported me. They were braver than me. I wasn't expecting that much from my friends but it was great, more than family.

Other participants too shared that they received sufficient support from family members and friends while some of them were able to arrange domestic help services for themselves.

Sara – I have full-time maid at home. I had help from long time. I did not like the Indian cooking that time so she helped me with that. One of my sisters or sister-in-law used to come and help over the weekend.

Nina – I took leave of absence from work and started working again post-treatment. My sister was with me so I had good support.

The above narratives show that majority of the participants received emotional support from close and extended family members and friends while some of the participants were able to afford domestic help as an additional form of support during treatment. In this regard, a diagnosis of cancer did not lead to a major shift in division of labor or domestic routines in their households, since the loss of domestic function was compensated by extended family members, friends, and hired domestic help. However, spousal contribution towards household responsibilities increased in cases where participants were not in a position to hire domestic help. Additionally, a relatively egalitarian division of labor had already been in existence prior to the diagnosis of cancer in certain cases, as reported by participants. Overall, the participants

presented a narrative of shared division of labor and flexible gender roles in their households which deviates from the findings in the literature that primarily focus on a gendered division of labor among Indian families (Rangaswamy 2000; Navsaria and Petersen 2007).

Family Roles, Forms of Support and Selfhood

Many participants also shared stories about their experiences regarding receiving care and caregiving which generally created a shift in caregiving roles between adult children and parents. This often involved caregiving behaviors and routines that often mimicked parental behaviors on behalf of adult children towards their ailing parents as described by some of the participants.

Nina – My family was supportive. My daughter became my mom at that time. I told my grandchild your mom became my mom.

Alex recounted a similar experience while undergoing treatment for cancer, Alex remarked that she was extremely emotional and depressed about her diagnosis of cancer. As a result, her son and daughter would go out of the way to boost her morale and ensure that she felt supported and cared for. Below, Alex shared one of the instances while undergoing chemotherapy.

Alex – My son came home one day. He kept a big jug of water in front of me and said mom, you have to drink it. This will go in and then it will come out but you have to drink it. He would take me to the park and make me sit on a swing like I was a kid. He would tell me mama, you have to fight. He said to me that mom, you have a good team. He held my hand and said everybody is caring for you.

Alex narrated similar instances regarding the care that she received from her daughter during her illness.

Alex – My daughter used to take me for chemotherapy. She was so young and yet she cared about me like I was her daughter. She once kept her hand in front of me when I threw up. She would sometimes switch off the television if some serious scene came on it *ke ghabrahat na ho jaye* (So that I do not become restless). She would also clean my room.

Alex's statements show that her children were particularly meticulous about caring for her and fostered an environment that was caring and nurturing towards her. Additionally, Alex also provided an insight into her emotions during her illness. She shared that she felt extremely emotional and often felt baffled at her diagnosis.

Alex – This disease is such that everybody in my family was emotional. I was very mad and angry from inside. I was like what is this! I hated the white coat. *Ghabrahat hoti thi.*

Kuch khane ko man nahi karta tha (I used to feel restless/nauseous). I used to not feel like eating anything) with chemo.

Alex's narrative posits her own emotional struggle with coping with her illness. During the interview, she shared that she constantly felt angry and upset about her diagnosis. Even though she had a cordial and trustworthy rapport with her doctors, she admitted that she hated seeing any health professional in a white coat because it reminded her of her illness.

While majority of the participants were primarily focused on dealing with the emotional and physical strain of cancer-related illness, Ben shared the distinct experience of being both a cancer patient/survivor and a caregiver for his ailing daughter. He shared that he took a break from work to care for his daughter.

Ben – I took days off to be with my daughter. I went to work when she got stable. Then, I was visiting her every month. Before that, when I was diagnosed with cancer, my daughter stayed with me for 2-3 months. She was healthy at the time. She had no clue that she would get cancer next year.

Additionally, Ben shared that he was diagnosed with cancer prior to his daughter's diagnosis. At the time, his daughter had been one of the primary caregivers for both her parents when Ben and his wife had not been keeping well due to different health reasons. Following Ben's remission, his daughter was diagnosed with cancer unexpectedly leading to the switching of caregiving between Ben and his daughter at different points in their lives. Thus, the participants' experiences showcase the exchange of caregiving roles among family members and

particularly among parents and adult children following a cancer diagnosis. Apart from receiving care from female members, the male members of the household also performed caregiving duties and demonstrated their support through nurturing acts. Hence, conventional gender norms did not uniformly apply to participants' in context of caregiving and domestic responsibilities in these cases. Additionally, the participants shared that they also provided financial support to family members who had been diagnosed with cancer.

Anil – I would visit my brother and also send him money for treatment since he was not well off.

Mona – We would send money to our aunt since she needed the financial help.

Anil's brother had been diagnosed with cancer. Anil shared that he would visit his brother in India and would help him with paying the medical expenses for treatment. Similarly, Mona's aunt had been diagnosed with cancer and was also residing in India. Both Mona and her mother were very close to her aunt. Hence, Mona would assist her mother in looking after her aunt in India, in addition to providing financial assistance. Such cases outline the significance of financial support in cancer caregiving since most individuals have to pay the medical expenditures out of pocket in India. Additionally, other participants such as Charu had also shared receiving both emotional, functional, and financial support from siblings. Hence, these vignettes illustrate the immense help that the participants received from their children and close family members.

Likewise, the participants also shared instances where they felt responsible for the well-being and normalcy of their caregiving children during their illness and treatment and hence demonstrate the reciprocal dynamic of caregiving present among patients/survivors and caregivers.

Joy – My husband was a big help. My daughter was a big support. I had to think positively about treatment and recovery. There was no other option. My daughter had her own business that she had to take care of. My son was in the last year of graduation. It was very important for me that he graduate on time. I wanted everyone to carry on with their lives.

Joy's statement shows that her feelings of concern regarding the impact of her illness on the lives of her children prompted her to orient her thoughts towards recovery and imbuing a resilient attitude towards her illness. This was evident in her statement about not having any option but to get better. Although this type of thinking can have a positive impact on the mindset of a patient, it can also place undue stress on individuals experiencing cancer if the recovery takes longer than expected or the prognosis turns poor. In addition, these experiences show that caregiving is a mutual process where both patients and caregivers internalize and express care for each other in varying capacities. This could range from performing functional household and personal chores to demonstrating active interest in one's recovery while withholding vulnerable thoughts to appear strong for the sake of the care receiving patient or the caregiving family member.

While most participant narratives were centered on accounts of caregiving and care receiving, and the psychological and physical strife of dealing with cancer, one of the participants, Tina, felt that caregiving was emotionally taxing for her as a patient/survivor due to the various opinions from family members regarding her diagnosis of cervical cancer. These introspections had unwillingly put her at the receiving end of overbearing suggestions regarding dietary recommendations which added to the stress of dealing with cancer.

Tina – It is like everyone has something to say. It was more like do not drink too many sodas or do not eat too much sugar. In my case, it was cervical cancer. It had nothing to do with whether it was drinking alcohol or whatever.

Tina's narrative illustrates that caregiving can also become a form of moral policing and control for an individual given the scrutiny on possible causes of cancer. Tina's case including those of Alex, Nina, and Joy posit age and one's kinship position in the family as influential factors in forming caregiving experiences among caregivers and patients/survivors. While Alex, Nina, and Joy experienced nurturing aspects of caregiving from their younger children, Tina felt smothered and patronized in receiving care from elderly family members with parental authority even though she was appreciative of receiving support from her family. Owing to this, Tina experienced instances where she felt that her agency and autonomy as an individual were compromised, whether it was her exclusion from her diagnosis or the smothering that she experienced on behalf of her family members. Tina's narrative shows that while receiving care and support from family members can boost the morale of patients and can be instrumental to their recovery, certain forms of caregiving although well intentioned can be burdensome and demoralizing for individuals in cases of excessive scrutiny family members.

One of the other key aspects that emerged during participants' narratives of caregiving was the theme of agency and the moments of self-reflection and transformation that they experienced as part of their journey with cancer. Sara's narrative about the impact of cancer on her personality and priorities rendered a positive and unusual insight on her experience with cancer. Sara shared that her diagnosis of cancer and subsequent illness was instrumental in helping her to focus on her needs as an individual and express her agency in close interpersonal relationships which she had not been doing prior to her diagnosis.

Sara – I was very upset when I was diagnosed. If you are asking me now, I think getting cancer was a blessing. I was a typical Indian mother, only thinking for the family. It (cancer) brought that clarity. I used to put myself on the bottom and everyone else was first. It is not like my husband does not love me but he used to do things his way. Small things, and he would always convince me to agree with him. It was the same thing with my kids. For example, if I wanted an hour for myself, I would not prioritize it. After getting sick, I got that clarity. I had the courage to say this is the way I want things to be.

Sara's thoughts on the changes in her personality and perceiving cancer as a "blessing" shows that a diagnosis of cancer was a catalyst for her to be assertive and expressive regarding her needs as an individual with her family. As per Sara, she had placed greater value on her role as a wife and a mother which changed after she possibly saw her time as limited in the initial stages of her diagnosis. Simultaneously, Sara also shared experiencing conflicting emotions of guilt and doubt with regard to longing for attention.

Sara – One year after the treatment, I was very doubtful and down. I would think no one cares because I was miserable inside. It was a little bit of everything. My kids were in school and my husband was going to work. Even though I was getting the best treatment, my husband was not there since he had to pick up the kids. He was doing his best but my mind was watching everything minutely. When you are going through a situation like this, you think you should be the priority. I was perceiving every little thing the wrong way. I was the victim. Even though it's your pain, nobody can share it with you. When you are on bed, you are watching everyone's behavior under the microscope.

Sara's evaluation of her thoughts shows that she was trying to achieve balance between communicating her needs to her family while attempting to not be overbearing and overly critical. Her state of mind and reflection on her emotions demonstrates the mixed feelings that an individual with cancer can experience with regard to feeling the need for care and nurturance while trying to be not burdensome towards one's caregivers.

The Emotional Impact of Caregiving

While participant narratives consisted of various instances that showed an exchange of courage and support among participants and family members, these vignettes also demonstrate the emotional strain and ethical conundrum that caregiving family members experience during the course of a cancer illness. The following narratives focus on the experiences of family members who were caregivers for cancer patients/survivors. These quotes narrate the deep and life-altering impact that cancer has on the minds and lives of caregiving family members.

As Alex was talking about the care and nurturance that she received from her children, she described the frame of mind for her son and husband during her illness.

Alex - My son told my husband, you have to keep her happy. You have to make her okay. This is when the biopsy results were not back. My son was very sad inside. Had we not seen the surgeon, it could have spread. My husband has a small heart. He used to be like as if he is sick, not me, but the kids would tell him that it is okay dad. Actually, my husband himself needed therapy and support. We did not go for counseling but the nurses used to talk to us on the phone.

Alex's statements show that she perceived her husband and son's experiences differently even though they both performed caregiving duties for Alex. While her son appeared to be collected about her illness, Alex could sense that he was deeply distressed about her condition. In contrast, her husband's stressful demeanor was apparent as he found it hard to restrain his emotions and cope with her illness.

Additionally, some participants shared that they had to polish specific skills as part of switching responsibilities with their ailing family members. For example, Eva talked about how she had not been comfortable with driving and it was her husband who used to drive majority of the time. However, Eva had to address her anxiety about driving following her husband's diagnosis since he did not always feel well enough to drive and she had to drive for doctor's appointments and other errands.

Eva – My husband was the one driving 95 percent of the time. At the time I was not 100 percent comfortable with driving. He liked driving. So, that changed. I had to drive. I would feel nervous but one of my friends said, it's okay. It's just driving. He used to also help so much with domestic chores. He could not do that anymore. He was very sensitive to smell. That was another reason why he was going to work besides keeping himself busy. I used to break down with house work. The home pressure had increased for me. I was working part time during his diagnosis. No one came to help with cooking or cleaning. You know, sometimes you are just tired and exhausted. We have a lot of family but we are scattered. There was support from very few people. I still remember them.

In addition to overcoming her phobia of driving, Eva's narrative also highlights the physical and emotional upheaval that caregiving family members experience while juggling different roles within a household. Similarly, Kate talked about the strain and conflict with regard to her varied roles and responsibilities within the same family unit while caring for her parents who were both diagnosed with cancer.

Kate – I handle all doctor appointments. I have not missed a single appointment of theirs. They tend to go into depression because of their sickness. I quit my job last June. I have a business now. I have kids and I am a single mom. My kids asked me if I can visit them but I cannot go. If I leave my parents and go, they think that I am leaving them. Indian families *mein aisa hota hai* (This happens in Indian families).

Kate's narrative shows the multiple challenges that she was facing as a primary caregiver for her parents, who were both diagnosed with cancer. She had to resign from her job as a full-time position was interfering with the caregiving responsibilities that she had to undertake for her parents. Kate was also struggling with being able to visit her children since her parents heavily relied on her to cater to their needs. When I inquired from Kate whether she could hire domestic or professional assistance or have a relative volunteer occasionally to tend to her parents, she replied that her parents were very selective about their diet due to the side effects of chemo and partially due to their temperament. She also mentioned that she had other siblings who could help occasionally but her parents preferred that she handle everything and were rather rattled by her absence.

Kate – My parents are picky about food. My dad is on a liquid diet. He cannot eat solid food. He cannot go to a restaurant even though he was always a foody person. I do things for them myself even though there is assistance because they are picky. My mom might be okay for 1 or 2 days but she does not even like my cooking sometimes, forget anyone else. I once told my brother and sister-in-law to stay with them for a few hours and they were calling me again and again.

Although Kate's case might be unique in terms of the extreme emotional and functional dependence that her parents had towards her, it highlights the immense filial piety and loyalty that she felt for her parents. When I asked Kate about what does she do to manage her stress levels, she replied that she often finds solace in cooking as a way to destress.

Kate - I like cooking. Otherwise I will go crazy. I would like to take a break for some time.

Kate's narrative depicts the strenuous emotional and functional demands that her caregiving duties require of her. Although Kate considered cooking as an outlet for ameliorating her stress in caring for her parents, she often felt restricted in her ability to spend time with her children and had expressed a yearning for travel and increased flexibility with her time.

Similarly, Grace shared that the period of caring for her father post his cancer diagnosis had been an extremely challenging and emotionally exhausting time for her family. Grace's case also highlights the challenges that individuals living abroad encounter in caring for elderly parents diagnosed with cancer. Grace's parents were residing in India when she came to know about her father's diagnosis. The following narrative outlines her struggle with juggling a full-time job and domestic responsibilities with attending to her father and assisting her mother with caregiving in India.

Grace – When my father was diagnosed, I was in U.S. I was waiting for the results. I was a mess. I spoke to a friend. She made me feel better. My sister could not go for his surgery so I went to give my mom a break as she had been taking care of him. He only likes food cooked by her so she was the one who was mostly cooking.

Grace's narrative illustrates how multiple members within a family unit have to sort through their own personal obligations towards families and job schedules and attend to

caregiving duties. This situation is more complex for individuals who are expected to undergo long distance travel to care for their parents. In addition, this case also depicts the strain on caregiving spouses and its collective impact on all family members. During the interview, Grace spoke about the impact of cancer on her father and its subsequent effect on interpersonal interactions among her family members.

Grace – It was hard to see him in so much pain. He was just not cooperating. I did not know if I should be sympathetic to my mom or to him. He was not listening to anyone. My dad has always been a very positive person but he was quite a mean man when he was sick. He was shouting at the doctors and nurses because he was in pain. He would tell us, “you are just waiting for me to die.” It was still hurtful of him to say those things to my mom even though he was in pain. I was patient but my sister would respond back. She would write down what he would say and she would show him his quotes. He would behave better and he would lose it again. The cancer has just changed him. Even now, he gets angry if we tell him not to do something but we tell him to be considerate of mom because she is the most affected. He forgets that this is not the old him. It is like handling a child. We cannot say anything directly to him. We have to beat around the bush.

Grace’s narrative highlights the trauma that her father was experiencing due to which he would often react unpleasantly to his family members and the medical staff. Her narrative also shows the immense frustration and predicament that her and her family members felt in caring for him while having to cope with his outbursts and frustration regarding his illness. Additionally, it depicts the different dynamics that can exist among family members in terms of

their reactions towards the patient/survivor. For instance, Grace had shared that she was patient and composed towards her father's behavior since she attributed it to his suffering, whereas her sister believed in accounting him for it and communicated with him about its effect on her mother, her sister and herself.

This case outlines the hierarchy that forms during caregiving among family members. Grace's mother was the primary caregiver for father since she resided with him and attended to him throughout his illness. Grace's father seemed to depend more on his spouse, based on Grace's narrative. In this regard, this case depicts the split in familial piety and loyalty that adult children feel between caring for a sick parent while feeling protective and concerned for the well-being of the other caregiving parent. Grace's statement about not knowing whether to support her father or her mother highlights the emotional dilemma that individuals encounter in caring for a sick family member while being empathetic towards the primary caregiver. As Grace stated, she felt that cancer had fundamentally changed her father and had had a long-term impact on how her family members had to communicate and behave around him. Grace and Kate's narratives highlight the emotional toll on caregivers in caring for ailing family members. Individuals often undergo a plethora of emotions ranging from guilt, frustration, and obligation to compassion and fear of losing their loved ones. Cancer as an illness has a collateral impact on both patients/survivors and caregivers in varying capacities.

External Forms of Support

With regard to seeking external forms of support, such as on-site counseling and online cancer community support groups, majority of the participants shared that they did not actively seek emotional and mental support through those channels. Most participants shared that they

relied on the support of family members and friends, while some also mentioned receiving support from colleagues and health care professionals in addition to family and social networks.

Grace – My husband was my biggest support. My friends and coworkers were so supportive. They would say they have had similar experiences. So I was like okay my dad is not being abnormally crazy. I did not seek any counseling or online support communities. My kids were very supportive.

Sara – I was aware of support groups. I used to talk to the head nurse. She introduced me to a couple of patients. I used to talk to them. It was helpful. Some people are verbal. I am not really verbal but I asked them how they coped with the fatigue and nausea.”

Grace’s statement shows that she relied heavily on her spouse and her children for emotional support to cope with her father’s illness. Alex, Charu, Cindy, Nina, Anita, Joy, Nita, and Seema made similar statements with regard to relying exclusively on their family members for support in coping with their own illness or the illness of a loved one following a diagnosis of cancer. Additionally, Alex shared that she had received a visit from members of the cancer support group at the hospital. However, they did not visit her at home since she was too busy with work and would often forget to contact them when I enquired if she had sought assistance from any online or in-clinic cancer support groups.

While the above participants quoted familial support as an immense source of strength, Kate had mostly been single-handedly caring for her parents who had both been diagnosed with cancer and hence was the primary caregiver. When I asked her if she had contemplated seeking

counseling as a way to manage her stress regarding her caregiving obligations towards her parents, she replied that she had received suggestions regarding counseling but she considered herself strong enough to not need it. I asked Kate if she is able to share her feelings with her friends so that she has some form of emotional support. She replied that she has supportive friends but she is the one who has to still take care of everything as caring for her parents is her responsibility.

Kate - They asked counseling for me as a family member. I said I do not need it because I am handling everything. I am ready for good or bad news. I will help my parents but we are suffering. I have a couple of friends who are supportive but it is like this. What can one do?

Interestingly, Kate's statements reflect a combination of resilience and vulnerability in coping with her parents' illness and the demands of caregiving that had been placed upon her as a result. On one hand, she equated personal strength with not needing counseling, while on the other hand, she also felt a degree of helplessness regarding her parents' and her own situation, which was evident in her statements "we are suffering" and "what can one do?" In her statement, Kate posited "we" as a collective representation of suffering which reiterated the collective impact of cancer on individuals as well as caregiving family members within a family unit.

Discussion and Theoretical Reflections

Insights into Familial Roles and Filial Piety

Majority of the participants shared that they received immense emotional and moral support from family members and wider social networks of friends and colleagues. Participants Anil and Mona provided financial support to family members who had been diagnosed with cancer. Therefore, structural support in the form of financial and domestic assistance was a key feature of caregiving for patients/survivors and caregiving family members. The findings from this section also support the prevalence of filial piety and values of feeling duty and loyalty towards one's parents in Indian families. Retrospectively, these findings also highlight the remarkable role that family members play in caregiving and recovery among patients/survivors among Indian families.

With regard to caregiving roles, some participants reported that their spouse was not contributing actively in domestic duties, whereas some reported that they had always received help from their spouse in household tasks, which only increased during diagnosis and treatment. The latter group deviates from the literature, which overall paints a stereotypical picture of gender roles where women are expected to shoulder majority of the household work in most Indian families (Rangaswamy 2000; Mehrotra and Calasanti 2010). These instances present a contrasting image regarding division of labor, where participants shared that it was not unusual for the male spouses to assist with cooking or for the women to take charge in managing finances and thus transcend the perceived gendered division of labor and gendered binaries among Indian families. The participants also shared that a more unified approach towards sharing domestic responsibilities was already in existence in several cases and only increased after their diagnosis of cancer. These insights from the participants redefine the stereotypical notions of division of

labor and redefine gendered binaries among Indian families. Having help due to financial stability or social support did not affect division of labor, irrespective of how the tasks had been divided.

Additionally, the participants underwent a shift in familial roles with adult children often switching caregiving positions with their parents, which was in accordance with the values of filial piety and a strong ethic of loyalty and duty towards parents. Lamb defines filial piety in the Indian context as the ethic of *seva* or service directed towards one's parents in reciprocation of their emotional and material investment in raising their children (Lamb in Sharma and Kemp 2012). These sentiments and values were often visible in the caregiving behaviors of adult children caring for their parents gathered from the narratives of Alex, Eva, Joy, and Ben. In addition, Ben's case was particularly unique since both he and his daughter had been caregivers to each other following their diagnosis of cancer during different times in their lives.

The Dilemmas of Caregiving and Participant Attitudes towards External Support

Zarit et al (1986) define caregiving burden as "the extent to which caregivers perceive their emotional or physical health, social life and financial situation as suffering due to caring for a relative" (in Große et al 2017). The expectations and modes of caregiving often involved immense amount of pressure and adjustment concerning personal freedom, job schedules, and interpersonal relationships in caring for family members, as evident in the cases of Grace and Kate. Similarly, Nita shared that her caregiving responsibilities and the stress of her father's illness had compromised her own health. In other cases, forms of caregiving were often symbolic of familial authority, such as in Tina's case who at times had to deal with scrutiny regarding diet and possible causes of cancer by extended family members. Similarly, Simi recalled that she had

to stand her ground with talking about her cancer diagnosis even though her family had apprehensions about her doing so.

Additionally, participants shared instances where patients/survivors and family members used stoicism and restraint from expressing vulnerability as not just resilience but also as a reciprocal gesture of care towards their caregivers. Nonetheless, both patients/survivors and family members were embedded in regimes of care where patients/survivors were expected to comply with familial and clinical routines of treatment while the caregiving family members were expected to fulfill the caregiving responsibilities placed upon them.

In response to the question on seeking external forms of support, many participants shared that they had not sought the aid of on-site and online cancer support groups. The choice of various participants such as Anita, Grace, Kate, Joy, and Nita to not seek counseling or support from cancer support groups resonated with almost all members in the study. Most participants felt that they had a sufficient support system in the form of family members and friends, which did not necessitate the need for seeking external sources of support. Also, participants such as Alex were caught up with juggling domestic and professional obligations with cancer treatments and medical follow ups which consumed most of their time in addition to dealing with the physical and emotional strain of undergoing treatment for cancer.

Additionally, many Indians do not identify with the need to access mental health care resources, as mental health issues do not receive much awareness in India. Family ties and social bonds are expected to serve as social support systems for providing emotional and functional support and hence a stronger value is placed on those ties as opposed to professional counseling services (Mahomed et al 2019). The participants' attitudes towards seeking external forms of support certainly reflected these issues. Although counseling and cancer support groups may

prove to be effective outlets for ameliorating stress related to coping with cancer and caregiving for both patients/survivors and family members, many participants either did not feel the need to access these resources. Additionally, some participants also shared that keeping up with treatments, caregiving, domestic and professional responsibilities did not leave much scope for seeking mental health resources. Kleinman frames caregiving in the clinical context as “not just tinkering with medicines but also mundane and burdensome but nonetheless meaning-infused practices of assisting with daily living that including bathing, toileting, feeding, support and just being there” (2013). In this regard, for the participants, cancer and its caregiving went further and beyond because it also entailed renegotiating interpersonal relationships, decisions regarding disclosure and treatment and redefining what daily living meant for the ones who were caring and the ones who were being cared for.

CHAPTER SIX:

FAITH, GOD, DESTINY AND KARMA

Studies have shown that positive beliefs about faith, religion and spirituality can significantly impact survivors' and caregivers' ability to cope with the experience of cancer. Spiritual and faith based beliefs and practices often serve as channels for coping with illness, and finding guidance and purpose for survivors following a diagnosis of cancer (Samson and Zerter 2003; Choumanova et al 2006; Yanez et al 2009; Cipriano-Steffens et al 2019). The following sections depict the various stages through which the participants' beliefs about faith and spirituality either stayed consistent or were altered following their diagnosis of cancer. These narratives show the distinct personal journeys that individuals undergo in their experience with cancer and the role of religious beliefs and upbringing in shaping notions of self-growth, strength, and healing with regard to cancer. Additionally, I have not capitalized the "g" in god as I have come across grammatical sources that find both forms acceptable depending upon whether one is referring to a monotheistic god or gods.

Patterns of Faith among Participants

The participants' personal attitudes regarding religion and faith differed on a case-by-case basis. Various participants observed that their relationship with god or religious beliefs did

not alter dramatically. For them, a diagnosis of cancer was about accepting the reality at large and doing what was necessary to manage and cure the disease. Majority of the participants in this group reported that they mostly adhered to their regular routines of worship and observed their faith based practices as they had been doing in the past, without inculcating any new practices or beliefs. The reasons ranged from being optimistic about the prognosis to being focused on doing whatever was necessary for treatment and coping with the illness in general.

Joy—There were just routine temple visits. I had a positive mind but I did not do anything extra.”

Nita – Religion or spirituality did not play a role. I did not even think about it actually. Even my father’s routine did not change. He did what he was doing earlier. He would still try to do yoga every day. He never used to like being dependent on anyone.”

Joy and Nita’s statements show two different states of mind during treatment. As a patient, Joy’s thoughts were more aligned towards keeping her composure and having a positive mindset towards her treatment. In contrast, Nita was more concerned about fulfilling her responsibilities and meeting her father’s needs as she was one of his primary caregivers. Hence, she did not lean on faith or religious thoughts and practices to cope with the stress of her father’s illness. Similar to Joy, Nita’s father also did not adhere to any new religious or spiritual routine. In contrast, Priya shared that she prayed for her grandmother once she came to know about her diagnosis even though she knew that her grandmother’s cancer was terminal.

Priya -I knew there was no cure, but I did pray.

Similarly, Eva stated that she too did not make any new changes to her daily routine of praying and felt that both people and god help during times of trouble.

Eva- Some people help and god also helps.

Among other participants, Nina and Tina shared that it was their family members who went out of the way to perform certain kinds of religious practices to pray for their well-being.

Nina—My brother’s oncologist friend said, ‘Calm yourself down. Think of god. I had a normal routine but my family did whatever they could. They did *mannat*, *hawan*, *path* (prayer) etc.

Tina –My mother in law did *badha*. They also did *hawan*.

Nina and Tina’s statements show that their family members performed *hawans*, in which a small pyre is lit, since fire is considered as one of the sacred elements in Hinduism and prayers are chanted while making offerings of food and other substances to it. *Mannat* refers to performing a type of religious ritual in which individuals take a pledge to donate to charity or visit a religious shrine, while *badha* consists of restricting oneself from something such as a certain type of food until a particular wish is fulfilled.

Other participants, such as Cindy and Julie, also emphasized the notion of acceptance and surrender regarding their diagnosis and illness as a justification for not feeling the need to observe specific religious practices to cope with stress.

Cindy–If things will happen, they will happen. There is nothing to be afraid of.

I had these beliefs early on from my family and my friend who was also diagnosed with cancer. I have seen her suffer a lot more.

Cindy's narrative shows that she felt a combination of acceptance and empathy since she had seen a friend undergo extreme duress and suffering due to cancer. Julie cited a similar approach as well though she shared that she often distracted herself with external social activities including religious practices to keep herself busy.

Julie - Majboori aur time sab sikha deta hai. We go to the temple. Puja path mein bhi time jata hai. Usi se man ko shanti milti hai. Uske bina patta nahi hil sakta. Jo bhagwan ne diya hai dukh, use sambhalna hai. India mein issue bana lete hain. Hamen to lagta nahi ke bimari hai. (Compulsion and time teach one everything. The time gets spent in prayers and religious practices. That is what gives the mind peace. A leaf too cannot move without his (god's) will. Whatever suffering god has given, one has to deal with it. In India, they make such a big issue. We do not even feel that we have a disease).

Julie's statement provides an insight into how she perceived people in India approached cancer in comparison to the United States. Julie felt that she had a relatively calm demeanor of

handling her illness, in comparison to the severity and distress that people experience in India. On a similar note, Nick shared that he tried to help his mother in every way that he could to mitigate her stress. This included visiting temples although he and his mother did not consider themselves to be particularly religious. Nick shared that they visited temples to show solidarity with his father's side of the family, and as a gesture of goodwill for his father's recovery who had been diagnosed with advanced cancer.

Nick—We tried to make sure to help mom with whatever we could. I remember visiting temples a lot during that time. I was never religious. My dad's side is pretty religious. I have never seen my mom go to temples. She just lights the lamp. She tried to keep herself busy. She would work, cook and help us with school work. All of us tried to keep ourselves busy.

In contrast to Nick and Julie, Kate expressed that she did not believe in performing any additional religious activities to cope with her parents' illness.

Kate—I am a really strong woman. I do not do extra religious stuff. Just regular things.

Kate's statement shows that she associated not performing religious practices with strength and resilience unlike other participants who did not particularly make the same association in spite of not adopting specific religious practices to cope with cancer. Overall, the participant narratives show common themes of acceptance, and in some cases a sense of surrender to a higher force, by not feeling the necessity to perform religious rituals or modify

their religious beliefs. These cases present a mostly neutral attitude towards religious beliefs and practices that did not undergo major transitions among these participants.

Themes of Affirmation, Self-Growth and Healing

The following narratives present a different set of experiences, in which the participants expressed an affirmation and strengthening of their religious and spiritual beliefs as a result of being diagnosed with cancer. Additionally, there were also cases where participants felt detached and disconnected with their spiritual beliefs due to feelings of denial and grief. These cases were mostly attributable to caregiving family members while participants who were survivors usually felt either neutral or more connected to their spiritual values. As Alex recounted her experience with cancer, she shared various instances where she felt that the physical pain and discomfort accompanied with the emotional strain of her illness was unbearable for her.

Alex—I have had such a bad experience. Once, I got high fever. It was 104. I had blisters in my mouth. I lost all hair. I started to lose it with the first chemo and that was shocking. The medicine made me gain weight which I have not lost. They said it will make you gain weight. I took another medicine and it caused joint pain, shoulder and arm pain. I had such pain one night that I could not sleep. I went and lied in front of the deity, and I said, *bhagwan, ya to aaj theek kar de ya khatam kar de* (god, either cure me or end my life today).”

During the conversation, Alex shared that she eventually received relief from the pain that she had experienced that night. Alex’s narrative speaks of the immense suffering that she

underwent due to her illness from cancer. Her narrative also depicts an instance where she connected her physical suffering to a spiritual experience. Alex's experience with cancer led her to deeply explore her spiritual thoughts and connection to faith and god. She shared that she began reading religious scriptures and books although she used to routinely light a lamp which entails lighting up a wick made from cotton or thread after it has been immersed in oil or Indian clarified butter (*ghee*).

Alex – I started to read religious books. I light the lamp every day before going to work. If I don't pay respect to god, I will feel I don't know how my day will go. I repent if I am rude to anyone by mistake.

Alex's account of her experience with cancer illustrates a deeper connection with the notion of faith and god through her exploring religious texts, imbibing a daily ritual of lighting the lamp, and a more acute sense of morality by being cognizant of her behavior towards other people. In this regard, Alex experienced a certain degree of spiritual and moral transformation in her experience with cancer. Similar to Alex, other participants also reported changes in their behavioral and spiritual outlook. For Anita, the process of coming to terms with having cancer and coping with the effects of the illness and treatment were synonymous with changes in her spiritual beliefs, social interactions, and personality.

Anita – I became spiritual. I felt I had, you know, the Krishna consciousness. I have questioned myself whether I was in denial about my condition. It is not just the cosmetic effects. I had no eyebrows, no hair. There was loss of muscle function. I was not able to

feel my feet. There is complete meltdown of infrastructure. For me, it was not the cancer but the medicine that was poison. I am still partially disabled. It has left me partially handicapped. I have permanent myopathy and neuropathy but change is the law of life. *Parivartan ko accept karna padta hai* (One has to accept change).

Anita's statement shows the connection that she established between the physical outcome of cancer on her body and the way that she eventually accepted and coped with the effects of her illness. She began by recounting the ways in which her body and her capability to function as a healthy individual had changed. Her statement "but change is the law of life" attributes a somewhat philosophical dimension to the physiological impact of cancer. Anita's account of her experience highlights how individuals often adopt a strategic response toward coping with cancer, in which cancer is seen as part of a spiritual evolution, a higher plan, as a path of growth or change, all of which are considered to be part of the greater human experience. This helps to attain a certain degree of distance and neutrality towards a condition that is extremely personal given its acute and long-term effects on an individual's body and social existence. Anita's inclination to inculcate a more detached approach in order to effectively cope with cancer was further reinstated by her statement below:

Anita – I made it a point to not read about it. What I knew, I knew. I surrendered the outcome to the divine. I am not a classic run-of-the-mill patient. Illness is determined by culture. I felt that being a first immigrant, I would have felt anxiety and fear, but was more reminded of my conviction. I hope I am able to live through my beliefs. I always believe everything happens due to *sanchit karma* (collective actions).

Anita's reflection on her feelings shows that she arrived at a certain rationale about not considering herself as a "run-of-the-mill patient" since she felt that she experienced increased affirmation in her spiritual beliefs instead of being overridden by anxiety and fear during her treatment. She also attributed the development of cancer partially to the notion of *sanchit karma*, or collective actions that produce a particular phenomenon or outcome for an individual and grant an individual to learn valuable life lessons from a given set of circumstances. Additionally, Anita shared that her need to socialize with peers reduced and largely disappeared as she felt that most of those interactions did not lend any meaning to her life.

Anita – Earlier, I was socially very active. I was part of a woman's group. That completely changed. And when you are gone for 1-1.5 years, then people also sort of forget you or forget that you exist. By that time, my mindset had also shifted. My need for active social life was not there anymore. I was focusing on meditation and myself.

As Anita's statement shows, she attributed the shift from maintaining an active social life to one that was increasingly centered on daily regimes of meditation and reading that she had incorporated as part of coping with cancer, and developing an increased focus on herself. In addition, Anita was not allowed to have visitors at her residence since she had a low white cell count and was prone to infections, which restricted social visits from family and friends. Hence, restricted social visits along with Anita's own proclivity towards privacy owing to her account of emotional and spiritual transformation led her to not seek social interactions and support. This was in direct contrast from some of the other participants, who were not obligated to restrict

social interactions due to their illness and even relied on social ties, indulging and support to cope with cancer. Likewise, Sara also relied on meditation, literature, and self-help videos to cope with her illness.

Sara – You have to stay positive. I used to watch self-help videos. Having a strong faith in your religion and belief helps. I used to meditate a lot. In meditation, you are with yourself. I am a very disciplined person so it was not hard for me. Reading good positive material can also help.

Additionally, Sara shared that her diagnosis had a deeper emotional impact on her husband while she was able to reconcile with the reality of her diagnosis due to her faith-based beliefs and her involvement with a spiritual organization.

Sara – My husband was more devastated than I was. Maybe it was my faith. I believe in god. Whatever happens, it happens for a reason. I was involved with a spiritual organization. When something like this happens, materialistically, you are fine but mentally you don't know who you are.

While Sara's narrative suggests a strong belief in god and that everything happens for a reason, her statement about not knowing who she was irrespective of material comfort indicates the mental ambiguity that she felt around her notion of self and identity. This statement underlines the challenging psychological process of coming to terms with her illness in spite of receiving medical amenities and treatment. Anita and Sara's cases show that meditation and

other self-help resources, such as self-help videos and books that inculcated feelings of self-empowerment, were instrumental in accepting the cancer diagnosis and dealing with the physical and emotional effects of illness among these participants. In addition, revisiting religious and spiritual tenets related to one's faith were consequential to feeling peace and emotional stability during treatment.

Similarly, Lily's case reflected her strong faith in god and her positive belief in being able to heal after her diagnosis and surgery. Lily had gone to India to attend a wedding in her family when she was diagnosed with cancer. Lily decided to proceed with surgery without telling all her family members, although she informed her son. When I asked Lily the reason for her decision, she replied that she did not have health insurance at the time and also her children would have asked her to return from India. In addition, she replied that she did not want to cause panic among family members and risk stalling the wedding.

Lily - I did not have insurance so thought the treatment would be difficult. I did not tell because my kids would just say to come back. The doctor said you need to do surgery now because it is spreading. I did not consult anyone. I just went ahead. *Mere man mein tha ke main theek hojaongi* (In my heart I felt that I will be okay). My son was telling me, 'Mama, do not do it.' He was crying. I told him god is with me. They removed the entire breast. I got support but I rely on god. He is the master. My will power was fine with his grace. *Maine bhagwan ko utna hi mana.* (I completely believed in god) *Paida karne wala aur marne wala hi hai.* (He is the one to give birth and take life). There was a lot of struggle after chemo. I had gained a lot of weight. Nails and hair, everything is affected. God will keep me okay. I just take god's name to keep myself happy. I try to stay happy.

Lily's statement shows that one of the primary reasons for her to pursue surgery in India was the lack of health insurance in the United States. Also, she took the initiative of making a decision for herself because she felt that her family members would panic and ask her to come back. Additionally, she felt the urgency to proceed with the surgery since the attending physician had told her that the cancer was spreading. Lily's unflinching faith and belief in a positive outcome was an additional driving factor in her decision to get the surgery. When I asked Lily about when the rest of her family members came to know about her diagnosis, she mentioned that her husband came to know after arriving in India. For most other participants, faith based and religious/spiritual beliefs were supplemental elements that helped them to cope with the process of cancer diagnosis and treatment. However, Lily's case presents a unique narrative because her faith was the dominant driving factor towards claiming her agency as a patient and making the decision to pursue treatment where and when she felt was necessary.

Trauma, Loss and Faith

While majority of the participants professed that they forged a deeper connection with their faith, certain participants also experienced detachment and loss towards their spiritual and religious beliefs owing to the loss of a beloved family member. Pari had lost her niece to cancer.

Pari – Although, my niece was very positive, at this point, it is hard to say anything because even the faith is shaken. Sometimes it feels that this was destiny and she was like a mission to us. Why did this have to happen? It changes your outlook. You live one day at a time.

Pari's statement shows that she felt unsure about her religious and spiritual beliefs because her niece's illness had changed her perspective on them. She was still trying to make sense of whether there was a profound reason for her niece to be diagnosed with cancer and for all close family members including her to experience her illness. Her narrative encapsulated a range of emotions from questioning the very diagnosis of cancer to pondering whether it was destiny or divine intervention behind the diagnosis. At the same time, Pari also shared that the experience of her niece's illness had taught her to focus on the present and take every day as it comes.

While Pari's narrative presents her feelings regarding her niece's illness, Ben's experience depicted the different emotions that he, his daughter, and other family members underwent while dealing with her illness. For instance, Ben felt that he was relatively quicker to accept his daughter's poor prognosis in comparison to his daughter and her husband.

Ben – In my daughter's case, they were all in denial (his daughter and her husband). I was with them when they were being explained the prognosis. All they were hearing was she will get chemo and she will be fine. My son-in-law, believing in Hindu horoscope, said she was not supposed to die. He was in denial till the end. I did not discourage them in a way because I thought it was a positive thought. She accepted when she had perforation. At the end, she realized two days before her passing that she was not going to survive.

According to Ben, his daughter and her husband were in denial during the explanation of the prognosis and felt that they were interpreting the information presented to them differently. There could be a possibility that Ben's personality and his experiences and background as a medical professional might have helped him to come to terms with his daughter's terminal illness. Speaking of Ben's statement regarding the horoscope, and based on my own experiences, it is a cultural norm among many Indian families, primarily Hindus, to have a traditional astrological birth chart made after the arrival of a baby. This birth chart supposedly serves as a blueprint for naming the baby, assessing marital compatibility, and as a general reflection of the individual's personality traits and future. Even for families who do not believe in the predictive ability of birth charts, they still get them made as part of tradition. Ben's son-in-law's example of using his wife's horoscope as a justification of denying her impending death showcases extreme despair and shock that he was experiencing at the likelihood of losing his wife. Likewise, Ben's daughter was only able to accept the reality of her prognosis closer to the end of her life.

Similar to Ben's case, Mary presented her and her family's viewpoints regarding her mother's death from cancer. Mary shared that her relationship with god had changed and that she felt extremely bitter about her mother's diagnosis. She felt that her mother did not deserve to pass away from cancer even though dying is inevitable and this had severely affected her ability to make peace with her mother's passing and her own faith.

Mary – I think my relationship with god changed. I have definitely lost faith. I do not think I got it back after that. It became very philosophical after that. *Ke it is prewritten, jo hona hai wo hoga.* (It is prewritten. Whatever has to happen, will happen). Sometimes I am like what does it matter? *Main pray karoon ke nahi karoon?* (Whether I pray or not?).

I struggle with it a lot. I talked a lot about this with my family. They said she could have suffered a lot if we had not prayed. My dad is depressed. I guess I am more like him. It still hurts as badly. I am still very angry. I have not made peace. I am still stuck. I get strange dreams. I see her sick face. I try to think of all the happy moments before that. I mean everyone has to die but she was such an amazing person. Why did she have to suffer like this? You (god) were going to take her anyway but why so much suffering? I do not understand that. I remember some of the happier times. I spent the most time with her in the hospital. I saw her suffer a lot. My brother said that during the last rites, when he closed his eyes, he saw her smiling and walking away. We still talk about her a lot. He looks at it positively. My sister does too. She would say mom is watching when anything good happens. About me, I do not know.

Mary's narrative highlights the different stages of grief regarding her mother's passing and how they affected her understanding of her faith and relationship with god. Mary's statement also shows that she questioned the notion of destiny versus human will because she felt extremely helpless and perturbed over her mother's diagnosis and demise. Her statement about "feeling stuck and not making peace" due to watching her mother's illness very closely in the hospital reflects her struggle with reconciling her mother's loss and her beliefs about god. Her anger and confusion over trying to make sense of the way that she had lost her mother, even though she was rationalizing the inevitability of death, is evident in her directly questioning god ("You were going to take her away anyway...") during the interview. Additionally, Mary's narrative highlights the different ways in which individuals struggle or reconcile with the passing of a loved one such as in the case of her siblings. Mary shared that her brother held on to the

esoteric moment that he experienced of seeing their “mother smiling and walking away” during the last rites. Similarly, Mary’s sister felt their mother’s presence and consoled herself by thinking that she was always watching over them, whereas Mary felt that she was still grieving just like her father. Mary’s case depicts a heartbreaking narrative where the loss of her mother to cancer had fractured her ability to heal and find consolation in the notion of faith and god. In this regard, the participant narratives present differing images of finding strength in their religious and spiritual beliefs, or distancing themselves from their understanding of their respective faiths owing to their personal journeys of healing, loss, and grief.

Provider Perspectives on Faith

Ben had the unique perspective of both being a health professional and a cancer survivor. His narratives showcase his approach towards his patients as well as his own thoughts regarding the role of faith and spirituality in healing.

Ben—Indian philosophy says I want this person to live long so do not give negative news. Sometimes, it works. Maybe there is a correlation between positive thinking and immune system. Otherwise, sometimes they (patients) do go into depression. Patients believe in faith even if it works or not. They say, ‘Doctor you cannot tell me anything. Only god knows when I am going to die.’ I support that. They know the ballpark area. They know their life is short. Most of the people have religious faith. More so at the end of their life. They do not become devout Christian or devout Hindu, but they become more religious. It is a coping mechanism. It is helpful. It is social dynamics. There is lot of help from the church, especially if the person is alone. Religion has a lot of role during crisis.

According to Ben, longevity is one of the desirable traits in Indian culture. It is not uncommon to bestow and exchange greetings pertaining to longevity, good health, and prosperity on social occasions. Similarly, many people believe in harboring positive thoughts regarding a loved one's health, especially when faced with a grave illness to reassure themselves and loved ones who have been diagnosed with cancer. Hence, in Ben's experience, his patients and family members considered positive thoughts as a way to be optimistic, cope with the cancer diagnosis and possibly safeguard themselves from depression. For these reasons, he also felt that people held on to their belief about a positive outcome for the patient irrespective of the prognosis, and often became more religious upon knowing their diagnosis in certain cases. In addition, Ben considered a probable link between positive thoughts and the immune system. Additionally, he shared that some of his patients had told him that he cannot predict their death, since according to them, only god would know the time of their death.

Lily and Alex's narratives about god being the only one to be responsible for life and death coupled with participants' faith in religious/spiritual beliefs reiterate Ben's statement. Additionally, Ben's statement about his patients "knowing the ballpark area" show that they were often aware of their prognosis but also chose to believe in positive thinking and religious/spiritual ideologies as a way to emotionally assuage themselves. He acknowledged the critical role of religion and the support provided by religious institutions in coping effectively with cancer. At the same time, Ben's quote about supporting his patient's beliefs reflect his willingness to give his patients an emotional space where they did not feel discouraged during treatment or in cases of a poor prognosis.

Speaking of his own spiritual/religious beliefs, Ben shared that he is always connected to spiritual thoughts and often found comfort in the teachings of Indian religious scriptures.

Ben – I am always spiritual. I do a small puja every day since school age. All family members did puja in a temple. They believe in faith. Hindu faith is simple. You die, you are reborn. It's that simple. I was doing some mantra every day. For me it did not matter, but it is something to fall back on. We do not know what happens, but according to scriptures this is what they say. My faith is still the same. Nothing has changed. Each doctrine is the same. I have attended even church to listen to what they talk. The philosophy is similar.

Ben's statement shows that he considered beliefs related to reincarnation and the circle of life and death reassuring. According to him, one of the core tenets of Hindu faith is believing in the continuity of life. Ben felt that these beliefs provided solace and hence were dependable even if human beings did not consciously know what happens after death. Ben felt that his own faith had stayed constant, in spite of his diagnosis of cancer and the loss of his daughter. Additionally, he believed in the common philosophies of religious doctrines and felt that the teachings were connected across various religious schools of thought.

While Ben's connection towards faith and spirituality was rooted in his personal experiences as well as the experiences of his patients, Ray attributed the belief in god to culture and emotions among Indians.

Ray—Majority of Indians are very emotional type. That is how people behave in a doctor's office. I see a lot of Chinese and Vietnamese. It is similar. They including Indians deal with the cancer better because they believe in god and say it is god's will. Americans are different. The situation of god's will is not there.

Ray's statement highlights that both Ben and Ray had observed the belief in god among their patients. However, Ben derived his approach from his beliefs as well as the experiences of his patients. For him, Indian philosophy regarding spirituality and the immortality of the soul was a source of consolation that instilled positivity among his patients and himself. Ray looked at the belief in god primarily as a product of emotions. He shared that overall Indian patients dealt better with a cancer diagnosis because they consoled themselves by attributing it to god's will, which brought a sense of surrender and was instrumental in making peace with the diagnosis. Additionally, Ray felt that this was also a common trait among Chinese and Vietnamese patients. Ray felt that American patients, here referring specifically to non-Asian patients, were different because they did not ascribe to the notion of god's will as strongly as Indian patients in his experience. Here, Ray was speaking from the perspective of cases where select Indian patients looked at a cancer diagnosis as part of destiny or god's plan which Ray felt was less common among non-Asian patients.

Discussion and Theoretical Reflections

Themes of Religion, Spirituality and Loss in Cancer

Majority of the participants such as Lily, Alex, Julie, Anita, and Ben expressed their faith in god, religious/spiritual beliefs, and the positive impact of resources such as spiritual and self-

help books, and videos in coping with cancer. Additionally, Lily's case illustrated how beliefs regarding faith were a stabilizing influence given the lack of inefficient infrastructure and resources since Lily did not have health insurance at the time of her diagnosis. Some participants such as Joy and Nina shared that they did not necessarily feel the need to pursue a particular religious routine as a remedial measure or as a coping mechanism for their illness. Additionally, Nita felt that their religious/spiritual beliefs did not play a role in coping with cancer. However, Pari and Mary were very vocal about feeling distant from their faith owing to the loss of their family members. On the other hand, Sara expressed feelings of ambiguity and loss of self-identity as a person. Sara's case resonates with the findings in literature where cancer survivors have reported feeling a loss of control, and feeling vague and confused about themselves as individuals (Leung et al 2013; Gillies and Johnston 2004). Anita emphasized the notion of *sanchit karma* or collective actions and their contribution to particular events in an individual's life. Similarly, Cindy emphasized that everything happens for a particular reason and it would happen if it is meant to happen.

In this regard, the participants' beliefs reflected a combination of religious/spiritual philosophy in addition to their personal perspectives on rationalizing a cancer diagnosis. Overall, the participants who were patients/survivors felt that their faith and personal outlook had contributed positively towards coping with illness and in some cases was even strengthened in their experiences with cancer. In contrast, a select number of participants comprised of family members felt removed from their faith owing to losing loved ones to cancer with the exception of Ben who represented both groups. The bereaved family members who expressed detachment and anger towards the notions of god and faith highlight the deep and long lasting impact of grief

concerning cancer and the ways in which feelings of loss get etched in the memory of caregiving members who could not experience the recovery of their loved ones.

Providers' Perspectives on the Role of Religion and Spirituality in Coping with Cancer

Ben's perspective as a provider emerged from a challenging personal experience and professional interactions with cancer patients, which had most likely contributed towards an affinity towards faith-based philosophy and the relief it provided in dealing with personal loss. In contrast, Ray viewed beliefs regarding god and god's plan as part of Indian culture and its inherent emphasis on emotions. Ben and Ray's perspectives highlight the role of religious/spiritual philosophy in coping with a cancer diagnosis and treatment regardless of the differences in their personal outlooks regarding the connection between faith and healing.

Ben and Ray's narratives relate to the findings in the literature regarding religion and healing in the Indian context. As Chattopadhyay (2007) notes, religion was an important component of diverse socio-cultural practices among various civilizations in India. Additionally, Ayurveda, the traditional medical system of India was known to emerge from Indian Vedic scriptures and hence, it was commonplace to combine medical practices with spiritual and religious activities based on historical texts. Given this cultural and historical overlap, it was not unusual to observe the acceptance and integration of these systems among the health care providers. Given the historical intersections between religion and health, healing traditions have also found a foothold among Indian immigrants in the United States. Thus, immigrant communities often actively participate in religious and cultural practices as a way to preserve their traditions and imbibe cultural identity in future generations (Rudrappa 2004). In this regard, religious and spiritual activities serve as a source of creating and increasing social support

networks among immigrant communities. Thus, accounting for the influence of religion on health and overall well-being imparts a holistic approach to the study of illness and the practice of medicine which was evident in participants' narratives of religious/spiritual beliefs and their significance in helping them cope with cancer.

CHAPTER SEVEN:

**SURVIVOR, FAMILY AND PROVIDER PERSPECTIVES ON BIOETHICS AND
CANCER DISCLOSURE**

In this chapter, I discuss the diverse views presented by patients/survivors, family members and health care providers regarding the disclosure of a cancer diagnosis from an ethical perspective. I present the viewpoints of participants regarding their ethical take on an individual's right to know about a cancer diagnosis. Also, this chapter presents key insights from health care professionals and their approach towards addressing cancer disclosure among their patients. The narratives included here underline the distinct positions and experiences that shape the discourse on cancer disclosure and bioethics among various stakeholders. Additionally, this chapter highlights the role of caregivers and close family members in making key decisions regarding cancer prognosis and treatment for their loved ones.

Patient/Survivor and Familial Perspectives on Cancer Disclosure

While some participants agreed that individuals should know about their cancer diagnosis under all circumstances, others expressed concerns regarding voluntary disclosure and emphasized that it differs on a case by case basis. For instance, Tina and Anil were in favor of disclosure of a cancer diagnosis to individuals and did not support the concealment of health information irrespective of any justifiable reasons.

Tina—I agree with disclosure of cancer. I think as a patient, one should know everything no matter what stage, or how old they are.

Anil – People should not hide it. Treatment becomes difficult. The cancer starts progressing.

As evident from Tina and Anil’s statements, both did not consider the individual’s age or the stage of cancer as viable reasons for withholding the diagnosis. Tina’s own experience with not knowing her own diagnosis right away could have played a part in supporting an individual’s right to know about his/her cancer diagnosis. Anil on the other hand expressed his concern regarding concealing a cancer diagnosis and felt that it was a legit obstacle to treatment and the overall recovery for individuals since it hindered the treatment process.

Likewise, Sara shared that she believed that the patient has the right to know about his/her cancer diagnosis though cultural and social backgrounds, and legal norms could influence decisions regarding disclosure.

Sara—The patient has the right to know. Sometimes, they do not tell the patient in India. They think it is the end of life. If the patient is not educated or cannot handle the diagnosis, then the family can chose to not tell. It also depends upon the patient and family’s background. Here, the doctor’s hands are tied. They have to do what is legally right. If the family gives in writing that they wish to not tell, then the doctor needs to honor that.

Sara's statement shows that she considered non-disclosure and withholding of health information as a characteristic that was ingrained in Indian culture. Although she supported an individual's right to access their health information, she also felt that there could be exceptions based on whether knowing about the diagnosis is going to be a detriment for the well-being of the patient. Additionally, she felt that health care providers needed to honor the requests of family members in certain cases even if they were legally obligated, as long as the family was willing to acknowledge their wishes in writing. Sara seemed to support the middle ground by supporting the individual's right to know about his/her diagnosis but also acknowledging the need to address the issue if cancer disclosure on a case-by-case basis. Thus, Sara's approach to the ethics concerning cancer disclosure was more flexible compared to Tina and Anil, who unanimously believed that there were no exceptions regarding disclosure. Similarly, Anita believed that patients should have complete information about their diagnosis and prognosis unless it is a very elderly person who might have fragile health.

Anita – I think they should tell like it is unless somebody is very old like 80 plus (over 80 years of age).

Additionally, Nita, who was one of the primary caregivers for her father, shared that even though the health care provider who was treating him favored that her father knows about his diagnosis, he still complied by her wish to delay relaying the diagnosis. Nita felt that the doctor supported her in her decision since they both shared a certain amount of rapport.

Nita –The doctor knew me. The doctor said it is up to you to decide the course of treatment. When I asked the doctor if it is curable, he said he could survive for 2 years or 3-4 years at the most but he survived more than that. The doctor would say you know better or I know better? He also honored my decision though he told me if it was my father I would tell him. It is kind of tough.

Nita’s narrative shows that the doctor strongly felt that her father should know about his diagnosis, evident in his statement that he would tell his father if he were in her place. In addition, the communication between Nita and the health care provider alludes to the negotiation that was occurring between them. She mentioned that she had tried to explain to the doctor that the decision to not disclose the diagnosis was a very tough choice for her. Simultaneously, the health care provider was aware that she was the primary caregiver and was severely emotionally impacted by her father’s illness. Additionally, Nita’s statement that her father survived longer than what the doctor had predicted demonstrates that she felt confident in her abilities as a caregiver and probably also felt that her decision to not disclose the diagnosis to her father had most likely contributed to his survival beyond the predicted timeline.

Furthermore, Nita’s statement shows that dealing with her own emotions about not disclosing the diagnosis had been an internal struggle for her. She felt that there tended to be a lack of awareness, fear, and denial regarding cancer when someone was diagnosed with it. Nita found this attitude to be emotionally taxing for family members who often hesitated to talk about their feelings and address their concerns. She referred to this emotional stress as a “slow poison” where “family members get used to the pain”.

Nita – People need to be more aware of it. We tend to ignore in India. They become used to pain. In India, they keep it to the family. They should talk to other people. It is a slow poison, it keeps eating you.

Here, Nita clearly seemed torn about not having her father know about the diagnosis but also shifting the accountability to the culture of not freely discussing a cancer diagnosis in India, which she felt perpetuated non-disclosure. Nita and some of the other participants' statements about "awareness regarding cancer" implied that, if people felt reassured about a cancer diagnosis not being a death sentence and that survival was possible, it would be instrumental in reducing the fear associated with it. While Nita seemed to be in an emotional space of moral and ethical tension, Priya was very clear about the disclosure of a cancer diagnosis to an individual as relative and on a case-by-case basis.

Priya – It is on a case-to-case basis. It is the family's decision because family knows that person more than anybody else. In Indian community, family takes care of that person. You do not break that person's spirit.

Priya's statement shows that she did not associate any moral or ethical ambiguity with the non-disclosure of a cancer diagnosis. This could also be due to the fact that she did not have to witness her grandmother's illness closely since she was in the United States during that time. However, Priya's perspective did not uniformly apply to other cases among participants since Mary was in favor of having an individual know about his/her diagnosis in spite of being one of the primary caregivers for her mother. In addition, Priya's statement about "breaking a person's

spirit” implied that disclosing a cancer diagnosis could have a detrimental effect on an individual and hence precedence should be given to the judgement of close family members. Majority of the participants endorsed a similar viewpoint about recognizing and respecting the role of family members although the participant presented different opinions on cancer disclosure.

Health Care Providers’ Perspectives on Cancer Disclosure, Law and Family

On Cancer Disclosure

With regard to health providers’ perspectives on cancer disclosure, Ben, Ray, and Max presented their experiences with patients and family members. Ben shared that he had come across cases where family members had requested him to not share the diagnosis with the patient. He shared the following case while recounting one such experience.

Ben– The family told me, ‘Do not tell my father that he has lung cancer.’ Sometimes, hiding information does not work. There are signs and symptoms. People google and it gives them some idea. I have been treating cancer. A lady had breast cancer. She went through chemo and the family said, ‘Do not tell her.’ When you get chemo, you are exposed to so many people. *Yeh cancer ka ward hai* (This is a cancer ward). Obviously they come to know. Even if the doctor says, you do not have cancer, they know.

In discussing his experience regarding requests from family members, Ben felt that it was rather hard to conceal the diagnosis in present times anyway because individuals can locate that information on the internet based on their specific symptoms. Additionally, the

patient can know from their clinical environment such as the ward where they are admitted or the medical staff.

According to Ben, hiding information was futile given all these possibilities and the fact that patients sense their diagnosis eventually in many cases. On the other hand, Ben also discussed cases where patients had expressed to him to not know about their diagnosis formally and had requested that information to be relayed to a family member.

Ben – Patient has expressed that if it is cancer, then do not tell me. Tell my wife, she will tell me. These are delay tactics but sometimes they will say I have changed my mind. If I know I can cure lymphoma, I will tell the family, do not deny treatment because it will work. But if chemo won't work, then the family can make the decision with what makes them happy.

In this particular case, the patient told Ben to share the diagnosis with his wife instead of him because he did not feel emotionally ready to hear the confirmation of the diagnosis that he most likely suspected. Ben felt that these were delay tactics in having to deal with a cancer diagnosis although he had also seen cases where patients had changed their mind and felt ready to talk to him about their diagnosis. In his statement, Ben also shared that he was flexible with his patients depending upon the details of that particular case. For instance, he shared that he had advised family members to not withhold diagnosis or treatment because the prognosis was good while he had let them decide the course of the treatment if the treatment was not giving positive results. When I asked Ben about how he approached the disclosure in cases where the family members were hesitant, he replied that he often tried to educate and ease their concerns over the

next couple of visits especially if the patient's condition required prompt medical attention.

Furthermore, Ben shared that he tended to reassure his patients by advising them to not focus on the diagnosis but the treatment.

Ben - If I do not tell on the first visit, I will educate the family on the second visit or couple of visits especially if it is severe. It is not like I am not going to tell them. I do not exactly say, it is benign. I just tell them that do not dwell on the diagnosis.

Additionally, Ben shared that requests concerning withholding the diagnosis from the patient or not letting him/her know right away was primarily a psychological/emotional issue that came from close family members who felt extremely vulnerable and scared about the diagnosis and the possibility of a worsening prognosis.

Ben - Well, basically it is a psychological issue. It comes from close family members such as brother, sister, or son. They say, 'He is everything for me. He will be depressed.' We have to involve nurses and social workers. There might be resistance for 1-2 days but usually people come around. There is so much variation in dissemination of diagnosis. If it is a slow cancer, people are like, 'We can delay it (the disclosure). Let him be happy for 3-4 months.'

According to Ben, there were cases where family members initially resisted sharing diagnosis though family members eventually agreed with disseminating the diagnosis to the patient. Additionally, nurses and social workers would also intervene in cases where family

members were unusually resistant for longer periods of time. Also, the type and stage of cancer was a critical factor in the dissemination of diagnosis. For instance, family members would often request providers to delay sharing the diagnosis if the form of cancer was not aggressive, since doing so implied that they were subjecting their loved one to stress and trauma. Furthermore, Ben noted that a similar pattern existed among patients who knew about their diagnosis: their approach differed based on the type and severity of cancer.

Ben - Cancer is just like any other illness but it is more profound depending upon type. Someone can live longer or shorter. It is a deadly disease, if say lung cancer, but on the other end of spectrum, someone could live longer from acute to chronic phase such as chronic leukemia. If it is glioblastoma of brain, people say, "I do not want chemo. I will go on a vacation and enjoy". They will be put in hospice or palliative care. It becomes symptomatic care. There are people who want to try every treatment because they have only 6 months to live.

Ben's statement highlights the different responses that he had received from his patients based on the type and stage of cancer. In this study, individuals who had a probability of a relatively longer survival were more likely to opt for treatment, versus individuals who had a shorter time frame to live. Ben had come across cases where his patients chose quality of life by choosing to go on vacation or spend time with their family instead of undergoing treatment because they did not want to deal with the side effects of chemotherapy in the limited time that they had. Such patients were also more likely to opt for hospice or palliative care over conventional oncology treatment. However, studies have shown mixed results with regard to

patient preferences regarding cancer treatment and quality of life (Brom et. al 2014). For example, according to Donovan et. al (2002) that patients with recurrent ovarian cancer were willing to undergo chemotherapy in spite of knowing that the cancer was not curable. On the other hand, Mack et. al (2010) noted that two thirds of individuals with advanced cancer were more concerned with relieving pain and discomfort instead of extending their life span.

Additionally, Ben shared a case where a patient with early stage colon cancer did not want to talk about his diagnosis to avoid feeling stressed about it.

Ben - One patient (Indian) with early stage colon cancer had completed treatment. He does not advertise that he had cancer. He wants to feel better. He does not say he is a cancer survivor and does not tell any other family member that he has cancer. It is a psychological cover up. It is all about belief. They do not want to say anything negative. If it is low grade cancer, they say. "I do not have cancer" every time they come. It is Indian philosophy. It happens in India more. Some people look down upon someone with cancer. People talk about diabetes and heart disease but not cancer because it gives negative impact. People want to be positive. Somebody who has lived with chronic leukemia for 20 years may not mind talking about it.

According to Ben, not talking about a cancer diagnosis or being in denial was a source of psychological comfort for some patients. Hence, the aforementioned patient did not even prefer to be addressed as a cancer survivor. Ben felt that this attitude primarily emerged from the belief that cancer represents more negativity in comparison to heart disease or diabetes. Additionally, Ben felt that this approach was more common in India. At the same time, Ben emphasized that a

patient who has been living with a more chronic form of cancer such as chronic leukemia may not eventually hesitate to talk about his diagnosis and experience with cancer. Also, Ben noted that a similar approach existed among non-Indian families in some cases.

Ben - American families also protect family members. A patient had low grade lymphoma. They do not want to believe psychologically that they have cancer. Even people who are born here, they have similar psychology although they do make individual decisions. They do not bring that many family members with them.

Ben's reference to a patient with low grade lymphoma underscores his statement about the type and stage of cancer as a prominent factor in talking about one's diagnosis. However, Ben also noted that non-Indian patients were more inclined to not involve too many family members and typically took individual decisions for themselves. This statement emphasizes the role of close family members in decision making among many Indian families, in Ben's experience.

Speaking of attitudes regarding disclosure, Ray echoed similar views as Ben on dealing with patients and family members.

Ray—When I was in medical school, it was that you got cancer, you can go home and just pray. People think that they need chemo and they will be sick for life. Here it is law, in India it is a taboo to tell someone that they are sick. That is how they are brought up. *Sanskar aise hain* (The values are like that).

According to Ray, there were individuals who were hesitant to discuss a cancer diagnosis because that is how people are brought up in India. He felt that the fear associated with a cancer diagnosis made it a taboo to discuss it while health care providers were required to let the patients know by law in the United States.

Ray - I do not tell the diagnosis on the phone. News is news. I do not make the news. Without diagnosis, I am not going to talk to them. My way is like the American justice system. I do not agree with doctors who do not share. My main responsibility is to the patient. I need to get consent. Primary care can do that. A lot of times they do not want to tell the patient. They are going to send them to specialists anyway. It is a liability if the primary care gives a wrong diagnosis.

As per Ray, his primary responsibility was towards the patient and he did not agree with health care providers who delayed sharing the diagnosis with the patient or let family members take charge of doing that. According to Ray, he needed to get consent from the patient in order to proceed with the treatment. In addition, Ray shared that primary health care providers refrained from sharing the diagnosis in some cases since they knew that the patient was going to see the specialist. Hence, this gave them the opportunity to honor the family's wishes regarding non-disclosure of health information. In addition, Ray was more firm about relaying the diagnosis directly to the patient irrespective of the prognosis or any requests for delay from family members in comparison to Ben who was relatively more cognizant of the feelings of family members given their role in caregiving and decision making.

While Ben and Ray spoke of attitudes towards cancer disclosure in relation to cultural norms, Max narrated a case where a language barrier added to the complexity of such situations. Max shared that he had come across a case where the patient already knew about his diagnosis and an attending physician was discussing options regarding treatment. The patient's son and daughter-in-law were translating on his behalf. The family members were in favor of treatment, but Max felt that the patient did not have much of a say in the matter.

Max—It was a charged situation. There was a language barrier. The son and daughter-in-law were translators and were pro-treatment. I do not know if the patient had much of a say. This is about giving years of life versus quality of life. You are walking a very fine line. Physicians take it at face value that that is what the patient wants, whatever is being translated by a family member. Translation services add more time to the visit.

Based on this narrative, Max found himself in an ethically ambiguous situation since he did not feel comfortable about intervening between the patient and his family members given their status as close kin and caregivers in addition to feeling limited by the language barrier. At the same time, he also suspected that the patient was not completely grasping the details of the conversation while the family members led the conversation instead of merely translating. When I enquired about hiring translators, Max replied that interpreters or family members can translate for the patient although translation services add more time to the visit. Additionally, Max felt that while family members play an important role in caregiving, what they say cannot be presumed as what the patient wants in certain cases. Additionally, health care providers have to

strike a delicate balance between increasing the life span of a patient versus improving his/her quality of life while trying to navigate decision making between patients and their caregivers.

On Family Support

Molly, Ben and Max agreed upon the significant role of family members in providing emotional and functional support to individuals diagnosed with cancer. All three health care providers acknowledged the crucial role of caregiving family members during treatment and recovery and acknowledged the need for involving family members when necessary.

Molly – Family plays a significant role. People who do not have a familial support system usually do not cope that well with cancer compared to ones one who do.

Molly's statement depicts the crucial role that families play in the overall recuperation and rehabilitation of cancer patients/survivors. She shared that individuals who did not have support and caregiving from families often did not cope as well with their illness as compared to individuals who did, based on her experience in treating patients with cancer. Similarly, Ben too shared the significant part that families play in aiding recovery but also felt that not every individual with cancer was as fortunate to have that support system owing to cases of fractured families that he had encountered during his practice.

Ben—Cancer diagnosis requires family's support so you have to include families.

Sometimes patients do not want to involve a lot of family members for something minor.

Family support is very crucial especially the first couple of weeks. It is very important

but not everyone is that fortunate because of fragmented families. Social workers help with home health care where they do not have a family support system.

In Ben's experience, he had seen cases where patients did not want to involve family members in decision making if the diagnosis and prognosis was not that severe or only required a minor procedure. Nonetheless, Ben acknowledged that family support came in handy even during times of relaying a cancer diagnosis to patients and particularly in the initial stages of dealing with the emotional and physical impact of the illness and treatment. In talking about his experiences with both Indian and non-Indian populations, Ben shared that usually social workers stepped in to assist with home care where patients did not have support from family members or required additional assistance. Similarly, Max also reiterated Ben's perspective regarding the role of family members and oncological social workers in imparting care to individuals diagnosed with cancer.

Max– The role of the family should be recognized. Oncological social workers are helpful in facilitating information.

In his statement, Max emphasized the need to recognize and value the role of family members in cancer care for patients. He also acknowledged that oncological social workers can assist with facilitating information regarding diagnosis and prognosis among patients in addition to providing care. Thus, Molly, Ben, and Max heavily underscored the value and role of family members in navigating crucial moments with handling a cancer diagnosis, providing care and

positively impacting recovery during treatment in majority of the cases among individuals diagnosed with cancer.

On Legal Obligations

In addition to presenting their experiences and perspectives on cancer disclosure and the role of family in caregiving and decision making, the health care providers shared their approach towards navigating disclosure-related situations with patients and family members. Ray shared that he was willing to discuss the case with family members if the patient provided his/her formal consent to do so, since he did not believe in non-disclosure of a cancer diagnosis or any subsequent health information.

Ray – As long as the patient allows to talk to family, I am happy to explain. They have to give permission on a document.

Based on Ben's narratives about being accommodating of family members' wishes to an extent, I asked him if he was concerned about any legal implications about his decision to do so in case a family member became ambivalent or did not approve of delaying the diagnosis anymore.

Ben – I trusted the family. They have a right to sue me. I thought they were trustworthy. Physicians have different ideas even if they come from medical school. By and large, all physicians have to share the diagnosis. You can give them some time. If a patient is

confused or very elderly, the physician has to explain to the family. There is no hidden agenda called for. Whatever 2-3 cases, I have done, it was based on faith.

According to Ben, he made those decisions based on his trust and rapport with the family even though he knew that they could sue him. Additionally, Ben felt that physicians can think differently even if they come from conventional medical training. He shared that all physicians have to eventually share the diagnosis, although the family members can be given some time since family members are an important part of decision making especially in cases where the patient might not be able to comprehend information or provide consent. Additionally, Ben shared that such situations become more complex when there is dissent among family members about disclosure or the treatment plan. Ben shared a case where the patient's spouse was not in agreement with his siblings regarding a medical procedure, which highlighted ethical and legal dilemmas in such situations.

Ben – The legal challenges are that patients have to decide the treatment plan. Even if family says, we do not want anything, it is the patient's decision. As long as the patient has good thinking capacity or next of kin, they can make decisions. Sometimes, it is a dysfunctional family. There was a case where the wife did not want something to be done for the patient. His brothers wanted to get the procedure done. Legally, the spouse has the right to decide. We as a physician have to follow what the wife says unless the wife has disability. The patient knew about his diagnosis but was mentally confused.

As evident from Ben's statement, the spouse had the legal right to take medical decisions since the patient was mentally incoherent and hence could not provide consent. Although this case was in context of a medical procedure, the same dilemma can also be present in cases of disclosure when family members might not mutually agree on disclosing information to the patient. Given the precedence of family members in decision making, I asked Max about his perspective on handling requests regarding non-disclosure and health information from family members. Max replied that he would consider such situations on a case-by-case basis.

Max – I think I would comply depending on the case. I would want to ask why you are wanting me to do that. Because it is scary for them. In terms of legal proxy, who makes the decision would have my hand tied.

As per Max, it was important for him to know the reasons that family members could potentially present requests pertaining to non-disclosure of a cancer diagnosis or related health information. Additionally, it would also depend upon who had the legal right to make a decision on the patient's behalf in case it is not the patient himself/herself. Overall, Max felt that he would try to reason with the family members in such cases although he fully acknowledged the feelings and role of family members in caring for their loved ones.

In another case, Lisa shared that she had been hired to translate on behalf of the patient and his family members. A patient had been diagnosed with cancer and his family members were visibly upset and concerned about the diagnosis. One of the family members asked Lisa to request the physician if they can delay sharing the diagnosis with the patient for some time. When Lisa conveyed this request to the health care provider, he tried to mitigate the family

members' concerns. Eventually, the physician decided to give them some time to sort their emotions and suggested to Lisa that she can choose to leave the room as he finishes relaying the diagnosis. That way, he would have completed his obligation of giving the diagnosis, while Lisa would not be obligated to translate it to the patient since she was not in the room. These situations underline the multiple effects of a cancer diagnosis and disclosure. The patients deal with the physiological changes and the emotional burden of a cancer diagnosis and the family members cope with the strenuous demands of caregiving. Finally, the healthcare providers have to navigate between both worlds where they have to provide feasible treatment to the patients while reconciling the family members' concerns for the patient and requests regarding disclosure in certain cases.

Discussion and Theoretical Reflections

Age, Stage and Cancer Disclosure

In this chapter, the participants presented their perspectives on cancer disclosure from a moral, ethical, and social perspective which took into account individual circumstances, age, culture and the legal framework. A select number of participants among family members and patients/survivors considered age to be the decisive factor for cancer disclosure. While Tina and Anil felt that the right ethical approach was for individuals to know about their diagnosis regardless of the circumstances, Sara expressed that the health care providers needed to honor the family's wishes, their background, and the overall situation, although she agreed on the patients' right to know about their diagnosis. Anita and Nita considered age to be an exception while Priya believed that the ethical approach differed on a case by case basis regarding cancer disclosure.

Although Ben, Ray and Max were cognizant of the legal obligation to provide complete medical information to their patient under HIPAA [Health Insurance Portability and Accountability Act of 1996] (Wu et. al 2012), their approaches in handling requests for disclosure of a cancer diagnosis differed based on their respective experiences. Among the providers, Ray expressed that his sole responsibility was towards the patient and he chose to not proceed unless the patient was aware of the diagnosis and was consenting to the treatment. Ben had a more flexible approach and was willing to give family members time to come around, although he too shared that eventually all physicians had to disclose the diagnosis.

Similarly, Max shared that while he was understanding of the family's requests of non-disclosure or partial disclosure, ultimately such decisions rested on legal guidelines and whether the patient was in a position to make a decision. Among the healthcare providers, Ben also cited the type and stage of cancer as a factor in disclosure and the acceptance of diagnosis among patients and providers. Additionally, a health care provider's decision to delay sharing the diagnosis with the patient or provide an extension to family members in doing so was an ethical act of compassion for family members which aligns with the literature on relaying a cancer diagnosis as an act of cruelty (Gregg 2003).

Patients, Providers, and Ethics of Cancer Disclosure

Another perspective to consider is that the question of a health care provider sharing or not sharing the diagnosis should not even exist because a patient should know their diagnosis undoubtedly as reiterated by Tina and Anil among other participants. However, there are instances where individuals have requested to not know about a cancer diagnosis although most

of them came around later as shared by Ben. Ben's narrative about patients' wish to not know about their diagnosis presents an interesting ethical dilemma for the health care provider. Either the health care provider has to choose between relaying the diagnosis out of a legal obligation or withhold it unless the patient feels ready to receive the diagnosis given that the provider by principle is obligated to act as per the patient's autonomy and welfare (American Medical Association 2020). One could argue that the provider needs to tell because the patient needs treatment. Yet, the provider also cannot come across as cold and disrespectful of the patient's feelings if he/she is emotionally fragile about their diagnosis.

Moreover, the provider needs to gain the patient's trust and build a rapport especially for an illness such as cancer that usually requires a long term collaboration between a patient and a provider. Ben and Lisa's narratives about the health care providers' attempts to reason and reconcile with the family members' concerns regarding disclosure during treatment are a testimony to such complexities. Additionally, the health care provider could consider a patient's request regarding sharing the diagnosis with the patient's spouse or closest family member. However, that does not absolve the health care provider of his obligation to relay the diagnosis to the patient.

On the other hand, non-disclosure or partial disclosure of health information concerning cancer hinders a patient's right to making crucial decisions about treatment or end of life arrangements. This also risks the possibility of not finding an outlet to express the discomfort and suffering resulting from the illness for not only the patient but also family members. Additionally, Max's observations regarding cancer disclosure in cases of language barriers presents a compelling case for not considering the viewpoints of family members as a reflection of the patient's wishes. Considering this, health care providers need to inculcate awareness

regarding foreseeing and managing potential communication pitfalls by informing themselves of the patient's geographic background (Hudelson 2005). Additionally, these goals can be achieved through widely incorporating diversity and cultural communication training among medical schools.

Furthermore, a uniform approach to bioethics does not apply effectively given the impact of multiple factors. At the same time, health care providers walk a very fine line between decisions regarding the patient's quality of life, increase in life span and collaborating with caregiving family members who are instrumental to the patients' recovery as confirmed in participant narratives. As Max noted, health care providers have to strike a delicate balance between extending the patients' life span versus improving their quality of life. Given these diverse and complex scenarios, my intention here is to not propose that an individual's right to medical information can be surpassed but to show that these decisions are not limited to and merely resolved by obtaining signatures on medical documents. These are negotiations that emerge out of social contexts and lived experiences of illness, and occur collectively among patients, caregivers and health care providers.

CHAPTER EIGHT:

CONCLUSION AND APPLIED IMPLICATIONS

Revisiting Research Objectives

As noted at the start of this dissertation, the existing literature on cancer disclosure indicates that it varies in some places, including Japan, China, Singapore, Spain, Greece, Sweden and Italy (Ni and Alraek 2017; Chittem et al 2013). This is particularly true of cultures that adhere to a familial model of decision making, where close family members participate in critical decisions concerning the disclosure of a cancer diagnosis and subsequent treatment (Chittem et. al 2013). Thus, my primary aim was to explore the patterns of cancer disclosure and communication among Indian immigrants in the United States. In addition, I wanted to study the impact of a cancer diagnosis on family roles and caregiving. Lastly, I wanted to explore how biomedical ethics intersect with cross-cultural beliefs of health and caregiving.

Key Findings

On Cancer Disclosure

As per the findings regarding cancer disclosure, the participants presented three types of patterns which aligned with the literature on cancer disclosure (Markovic 2004; Chittem et. al 2013). Based on participant narratives, the disclosure patterns included full, partial, and non-disclosure of a cancer diagnosis. Full disclosure pertained to cases where participants were aware

of their diagnosis and chose to share that information with family members and wider social circles. Partial disclosure referred to cases where participants chose to disclose their diagnosis to some family members, such as spouse or siblings, but not others such as children or parents within the same family unit. One of the key findings from the study was the participants' understanding and portrayal of resilience in relation to the disclosure of a cancer diagnosis. Participants equated non-disclosure or limited disclosure of a cancer diagnosis with resilience in cases where they felt that they did not require pity or sympathy from extended family members and wider social networks. In such cases, the participants expressed that they were capable of dealing with their illness on their own.

Additionally, participants showed resilience in context of presenting a stoic demeanor to their family members. Participants refrained from displaying vulnerable emotions and thoughts regarding discomfort, pain, and stress to caregiving family members in such instances. In contrast, there were cases where participants used their agency to defy norms of non-disclosure present within their families and larger social networks. In such instances, the participants were not concerned about being pitied and sought social support to cope with their illness. These findings reflect what Scheper-Hughes (2008) defines as "tactics of resilience" where the display of a stoic demeanor and emotional control is considered to be synonymous with expressions of dignity and rational behavior. These findings presented multiple facets of how the participants understood and expressed resilience in cancer illness.

In addition to exploring participants' views on cancer disclosure, this study also looked at their understanding of cancer. The purpose of this exercise was to gain insights regarding how participants perceived cancer as an illness and as an experience beyond its existing medical definitions. Therefore, I asked the participants to compare cancer to an inanimate object during

the course of the interview. While some participants responded by saying that they did not really think of cancer as anything other than a disease or “just cancer”, many others responded by comparing cancer to a cactus with thorns, a form of poison, a snake, a cockroach, a sticky slime like substance that does not come off or a bug that can be squished among other metaphors. Among these examples, Tina, the participant who compared cancer to “a bug can that can be squished” had a case where she was completely cured while another participant, Daisy who compared cancer to “slime” had lost a close family member to cancer. Thus, in her memory, both the cancer and the grief of losing a loved one were like slime that was hard to get rid of.

Hence, these descriptions in the form of metaphors provided key insights into the participants’ perception of cancer and how their respective experiences with cancer had shaped their understanding of cancer as a disease, as an illness, as an experience and as a memory. Although, metaphors can also serve to detract from addressing pertinent issues regarding a critical illness such as cancer. Given this, Sontag has rightfully called for de mythicizing cancer (Sontag 1978). However, Lakoff and Johnson (2008) have underscored that thoughts which form the foundation of concepts are not just an intellectual exercise. They embody everyday functions and the ways in which we perceive and relate to our everyday world and the relationships that inhabit it. In this regard, the participants in this study have not used metaphors as a cloak to conceal cancer but rather as an instrument of expression to provide an enriched understanding of their experience with cancer as an illness.

In addition, the participants’ beliefs about faith, spirituality, and God were instrumental in coping with cancer although some participants expressed feelings of anger towards God and detachment from their faith due to their diagnosis, or the loss of their loved ones to cancer. Other studies have also presented similar findings regarding the strategies that patients/survivors adopt

in effectively coping with cancer (Molina et. al 2014; Mahomed et. al 2019; Cipriano-Steffens et al 2019). Overall, faith and religious/spiritual beliefs were a form of mental support for majority of the participants in addition to relying on stress management, optimistic thoughts and social support networks to lower emotional stress related to cancer.

On Caregiving, Family Roles and Therapy Management

Majority of the participants received emotional and functional support from caregiving family members. Many participants shared that familial roles were reversed between parents and adult children. Furthermore, many participants spoke about sharing domestic responsibilities with their partners and children during their illness, although some participants shared that this kind of arrangement had also existed prior to a cancer diagnosis. Thus, caregiving experiences displayed contrasting themes of filial piety, nurturance, and sharing of domestic duties on one hand while dealing with stress and caregiving burden in patients/survivors and family members experiences of cancer. The literature on filial piety and caregiving supports similar findings as presented by Lamb in Sharma and Kemp (2012) and Zarit et. al in Große et al (2017). Lastly, a select number of participants displayed the theme of resilience in their decision to not pursue external forms of support such as counseling and on site and online cancer support groups.

Furthermore, the participant narratives on caregiving experiences highlighted the crucial role that caregivers play in providing care, mediating therapeutic decisions and serving as a communication bridge between patients/survivors and health care providers. Similarly, Kleinman (2013) highlights the significance of caregiving as an act infused with meaning and socio cultural context outside of the mundane activities of clinical treatment and hence forms the moral core of medicine and what medicine needs to be. Additionally, these findings aligned with the literature

on therapy management, in which Janzen (1987) posits that family members and friends form a “therapy management group” for an individual when they lend moral support, assist the patient with communicating with the medical staff, and devise treatment plans with health care providers.

On Ethical Perspectives Regarding Cancer Disclosure

With regard to participants’ opinions on ethical perspectives on cancer disclosure, some of the patients/survivors and family members considered age to be a decisive criteria for withholding a cancer diagnosis. Other participants expressed their disagreement with non-disclosure regardless of age or any other factors and emphasized that a patient deserves the respect to know about his/her diagnosis. Among the healthcare professionals, type and stage of cancer was an important factor in considering the family members’ requests regarding non-disclosure or limited disclosure of a cancer diagnosis. However, two of the health care providers cited age as an additional reason while one healthcare professional did not agree with non-disclosure of cancer diagnosis or health information. All healthcare providers unanimously agreed with eventually sharing the diagnosis with the patient.

The participant narratives on disclosure highlight the intersection between cancer disclosure and age in relation to their perception of ethical choices. These narratives showed that age was a malleable factor above any of the other reasons such as relationship to the patient/survivor, familial hierarchy or geographical location that could potentially influence the disclosure of a cancer diagnosis. For instance, age was a factor that was presented as a justification for partial or non-disclosure of a cancer diagnosis by participants such as Nita and Priya, even if they themselves believed in the right to know about a cancer diagnosis. On the

other hand, participants such as Bela, Kiran, Tina, and Simi were vociferously in favor of an individual knowing about his/her cancer diagnosis regardless of age. However, Charu shared that in retrospect, she would not have made a different choice with regard to not sharing her husband's diagnosis with him given her understanding of him and her personal circumstances.

These narratives present diverse perceptions that exist regarding age and aging. For instance, the narratives that supported non-disclosure due to advanced age most likely stemmed out of altruism, compassion and protectiveness for a loved one, also noted by Gregg (2003) and Chittem et. al (2013) However, they also portrayed aging as infantile, patronizing, and fragile, a time in which an individual might not even have the opportunity to exercise his/her agency when faced with a chronic and high risk illness. These sentiments were starkly evident in Priya's narrative when she shared that her grandmother had not been pleased with knowing that her diagnosis was held from her. Similarly, Nita's narrative of her father conveying to her that he knew about his diagnosis and that he was okay. Furthermore, he exercised his agency by declaring his choice to not continue the treatment anymore. Additionally, these findings challenge the existence of a universal bioethical model as argued by Good et. al (1990) and underscore the need for a culturally conscious clinical practice that is cognizant of both a patient's and caregiver's respective sensibilities in dealing with illness.

On Patient and Provider Communication

Additionally, participant narratives presented key insights on the influence of patient and provider communication on the development of trust and rapport with patients/survivors and family members. The cases of Alex and Tina, among other participants, showed that the health care providers' attitudes influenced participants' feelings and reception of their diagnosis. For

instance, Alex had shared that she was able to follow through with her treatment due to her ability to trust her health care provider. Similarly, Tina's concerns regarding her diagnosis were ameliorated after addressing her concerns to her health care provider in spite of her family's projected fear of her diagnosis of cancer. On the other hand, participants such as Eva and Mary felt stressed about the illness of their loved ones due to unsatisfactory experiences with the health care providers. Additionally, the communication and bedside manner of providers was crucial in facilitating conversations about cancer disclosure and decisions regarding treatment among some participants. Brincks et. al (2010) and Schildmann et. al (2013) have espoused similar findings regarding positive treatment outcomes among patients based on effective communication and trust with their health care providers. Overall, individual or familial beliefs regarding disclosure were independent of the patients and families' level of satisfaction with the providers and the amenities received at medical facilities in most cases.

Methodological Applications and Lessons from the Field

This project was designed as a qualitative research study that utilized semi-structured interviews to explore and understand participants' lived experiences with cancer. During the study, I realized that conventional participant observation was not possible since the participants were not part of any cancer support organizations or support groups. This was beneficial in terms of letting me focus exclusively on one on one interviews and extract deep insights regarding cancer disclosure and illness. Alternatively, I was also able to observe reactions concerning diagnosis of cancer among Indians through social media platforms. Thus, this study illustrates the possibility of exploring alternate avenues of observing social and cultural interactions when conventional participant observation might not be possible in cases of sensitive topics of interest.

Theoretical Contributions

Most studies have focused on studying cultural attitudes regarding disclosure of cancer diagnosis among patients from other populations. However, there is limited research on Indian immigrants with regard to cancer (Hossain et. al 2008). This study expanded on the understanding of social and cultural processes that contribute to the lack of disclosure regarding cancer. For instance, Kleinman (1998) highlights illness as a byproduct of the larger socio-cultural environment where the concerned disease is just one part of the underlying pathology that produces a particular health condition. Similarly, Scheper-Hughes and Lock (1987) emphasize the interconnection between the physical body and the social life which collectively form a part of human existence.

In acknowledging this unified existence, cancer disclosure is a subjective and fluid process that requires an understanding of the complex social, therapeutic and etiological factors that shape it. In this regard, this study presents the influence of these factors on the lived experiences and illness trajectory of cancer patients/survivors among Indian immigrants in the United States. Furthermore, this research study fills gaps in anthropological literature concerning etiological beliefs associated with cancer among a select group in this population. It informs the literature on the collective illness experiences shared among cancer patients/survivors and caregivers in the community.

These findings contribute to the growing body of literature that recognizes the role of caregivers in long term illness management and rehabilitation (Kleinman 2013). They underline the participation of caregivers as a critical component of therapy management in cancer care within the Indian community. However, this study simultaneously highlights the “regimes of care” that patients and caregivers are subjected to in adhering to treatment protocols and

collective decision making processes among family units which represent contrasting images of an exchange of care and power. These findings draw from a Foucauldian approach regarding how sociocultural notions and medicalized care produce disciplined forms of caregiving and care receiving. Additionally, this study explicates perceptions regarding aging and their impact on cancer disclosure in this population. It highlights age as a decisive factor in navigating the moral ambiguity and ethics of cancer disclosure among caregivers in cancer care. In presenting these insights on lived experiences of cancer among Indian immigrants, this study posits the need for an informed bio ethical framework and practice that accounts for the role of patient agency while acknowledging the contribution of caregivers in cancer care in medical anthropological literature and clinical practice.

Applied Implications

According to Hemminki et al (2014), the rates of cancer incidence increase within a generation or two in the host country among various immigrant groups including Indian immigrants in the United States of America and Australia. As per the Swedish cancer registry, Indian immigrants are susceptible to lung cancer and gall bladder cancer (Hemminki et al 2014). Additionally, there is an increased risk of oral cancer among South Asians owing to the cultural practice of chewing tobacco with betel leaf (Ahluwalia 2005). Asian Indian and Pakistani women have a higher incidence of breast cancer especially above 40 years of age as compared to white women. Less than 60% of Asian Indian women age 40 and above tend to undergo regular clinical breast exams and mammography tests (Wu et. al 2006). Asian Indian immigrants who have resided in the United States longer than 10 years are more likely to adhere to these screening practices than recent immigrants (Wu et. al 2006). Given these statistics, beliefs

pertaining to cancer disclosure play a vital role in documenting family and medical histories of cancer. Moreover, this knowledge is critical to seeking appropriate screening practices among individuals in this population.

Also, there is a lack of an effective patient-physician communication model that accounts for the relationship between cancer-related disclosure practices and sociocultural models of caregiving in the Indian immigrant population. This study will be used to devise strategies for building medical and community-based support aimed at expanding awareness regarding cancer. The results of the study will be shared with health professionals, including physicians, to encourage the creation of a culturally-informed model of health communication through the facilitation of interdisciplinary seminars. The findings of the study will be shared through peer reviewed publications, professional conferences, local health clinics, and government agencies such as the Centers for Disease Control (CDC). In addition, the findings will be useful in the design of research initiatives for other immigrant populations, such as Korean and Persian immigrants, where similar cancer-related disclosure practices are prevalent.

Recommendations

The study's findings show that cancer disclosure is a multifaceted phenomenon that involves various stakeholders such as patients/survivors, family members and health care providers. Additionally, the study highlights the important role that family members play in providing critical cancer care and the recovery of their loved ones. While conventional biomedical care highly emphasizes notions of patient autonomy and decision making, this study demonstrates that key decisions regarding care and treatment often involve primary caregivers in the Indian community. Given the presence of these factors, health care providers need to devise

culturally sensitive communication in relaying a cancer diagnosis to this population. This implies that health care providers strive to inform themselves with the cultural sensibilities of their patients and caregivers. Additionally, the providers need to be empathetic and conscientious towards the viewpoints of their patients and caregivers. Although, health care providers may encounter situations where there might be differences in the approach towards cancer disclosure among patients/survivors and caregivers, this study also demonstrated that developing trust and rapport had a positive impact on both patients and caregivers in dealing with the trauma of cancer illness and following treatment plans. The presence of trust and communication between providers and patients have a beneficial effect on preventive measures such as cancer screening outcomes and long term treatment among patients (Villani and Mortenson 2013; Hudelson 2005 and Katz et al 2004).

In consideration of these findings, medical schools should encourage students in training to grasp cultural nuances that exist among various patient populations in an increasingly diverse society. Moreover, this kind of training needs to extend beyond the conventional approaches of “cultural competency” which refers to knowledge, skills and training and include a critical consciousness for the relationship between socio cultural issues and health care (Kumagai and Lybson 2009). This can be achieved by fostering partnerships between local medical schools and community based organizations that enable medical students to acquire cultural knowledge and language based skills that can be applied to working with diverse communities. For instance, the faculty at Rush Medical College developed a training program in alliance with a community based organization to inform undergraduate students about the local Latinx community (Nora et al 1994). Similarly, the University of Michigan Medical School offers the following courses as part of providing multicultural education through their course on Clinical Foundations of

Medicine (CFM). Additionally, the medical school teaches a course on the Family Centered Experience (FCE) which involves medical students documenting illness stories of patients at their homes (Kumagai and Lypson 2009).

Additionally, the findings from the study showed that although, majority of the participants relied heavily on social forms of support through friends and family members, there were also cases where the participants experienced extreme duress as primary caregivers in providing care to their loved ones. Therefore, health care providers and clinics need to make a proactive effort for encouraging counseling among patients/survivors and family members considering that Indian immigrants are less likely to seek it despite undergoing immense emotional and physical strain following a cancer diagnosis.

Also, telephone based counseling services can be provided to families in cases where patients/survivors and caregivers may face barriers in accessing walk in counseling services owing to hesitation and professional or domestic commitments. For instance, the Caregiver Life Line (CaLL) was a phone based counseling service that was shown to be effective for stress management among caregivers of hospice patients (Kilbourn et al 2011). Similar models can be adopted for cancer counseling for Indian immigrant families to cope with the physical and emotional stress of cancer care and treatment among patients/survivors and caregivers. Moreover, volunteer based counseling services from qualified community members can be beneficial in addressing issues of lack of access to health and language barriers in the community.

Additionally, these findings challenge the existence of a universal bioethical model as argued by Good et. al (1990) and underscore the need for a culturally conscious clinical practice that is cognizant of both a patient's and caregiver's respective sensibilities in dealing with

illness. To this effect, this study calls for a broader emphasis on the concept of “ethno ethics” that accounts for the moral issues concerning therapeutic interventions in non-western populations (Sharif and Bugo 2015). While “ethno ethics” as a concept offers an alternative viewpoint to the idea of universal autonomy, it also stands the risk of cultural essentialism and stereotyping (Good and Hannah 2015). Hence, moving beyond the dichotomy of western and non-western categories, we need to strive for a medical system that is aware of and open towards patient and caregiver sensibilities towards illness and therapeutic care, and is willing to account for those on a case by case basis wherever necessary.

Limitations and Future Directions

Given limited time and the challenges with recruitment, the study had higher number of women than men. I intend to recruit more men as part of extending the study to gain a better perspective on the illness experiences of Indian immigrant men. Similarly, I would like to continue interviewing more health care providers to further explore their experiences about cancer disclosure and bio ethical perspectives on the matter.

Conclusion

Cancer is a cluster of diseases in its etiology and biological trajectory. Moreover, various types of cancers have different pathways pertaining to type, stage, survival and prognosis where genetics and social environments further mediate an individual’s response to the illness. Therefore, given the complexity of cancer as a disease and its long term physical and emotional impact on patients/survivors and caregivers, these narratives portray disclosure as a contested domain among patients, caregivers and providers where the clinic is a social site for negotiation.

At the same time, the experiences documented in this study expound on the collective participation of these stakeholders in social and medical journeys of healing and documenting lived experiences of cancer. Therefore, neither a disease nor its treatment can be isolated from its social and historical roots. Hence, it is important for medical communities to consider the response to a cancer diagnosis and treatment in a socio-cultural context to effectively study cancer incidence, and develop a therapeutic and bioethical framework that accounts for socio-cultural sensibilities.

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