Cancer, Dying and Care: Ethnography of Palliative Care Practices

Thesis submitted to Jawaharlal Nehru University

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DECLARATION

I declare that the thesis titled **'Cancer, Dying and Care: Ethnography of Palliative Care Practices'** submitted to the Jawaharlal Nehru University in partial fulfilment of the requirements for the award of the degree of **Doctor of Philosophy** is an original research work and has not been submitted so far, in part or in full, for any other degree or diploma of any University/Institution.

Pooja Sharma

CERTIFICATE

We certify the above and recommend that this thesis be placed before the examiners for evaluation and their consideration for the award of the degree.

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Table of content

Abstract

This thesis is about care and dying. Drawing from ethnographic research conducted with a palliative care organisation, extending its free of cost home-based care services to the people living with cancer in Delhi and NCR, the study is primarily an enquiry into the role of palliative care in the lives of cancer patients. The work intends to raise questions pertaining to the general ontology of life's existential questions in the event of grave sickness. The idea is to critically engage with the stories by the means of ethnography and attempt a narrative which talks about, as the title suggests, cancer, dying, and care. The title mentions dying instead of death for the particular reason that the thesis observes the process of dying as well as the event of death instead of solely focusing on death.

The everyday quest for living or surviving with cancer, while simultaneously negotiating the extant cultural and spiritual notions of acceptance of death as an integral reality, alters the meaning of life for the people who live with such a condition. I am exploring the social life of the dying and how care practices impart meaning to their understanding of the disease, disability and death. External interventions like palliative care services when combined with home-based care shape the experiences of those living with advanced cancer and awaiting death. The precariousness of life, therefore, draws attention to the care framework that sustains living through the uncertainty of impending death and routine challenges of coping with physical debilities and disabilities. The social life of dying, thus, relies on care negotiations, while the situated realities of care and death are further contingent upon factors like resources and actors as well as choices, values, beliefs and perceptions. I

explore the interplay between these realities and the factors influencing their occurrences so as to figure out an understanding of living while dying. The inadequacies in the literature on the socio-cultural life of cancer-related care, death and dying in the context of the Indian sub-continent make such an exploration more relevant.

Whenever an ethnographer ventures into the field with a set of research objectives, much meets the eye when compared to the critical engagement of issues addressed in the literature, which in the present case is largely western literature. The reliance on western literature is for the reasons that the concept of palliative care has its origin in the western world. The scholarship within American anthropology is largely concerned with care practices (and aging), whereas the British sociological departments have a renewed focus on death and dying studies. The Dutch universities as well as the school of science and technological studies across the Continent, on the other hand, are engaging and addressing the conceptualisation of care. Accounts of similar critical engagements have recently emerged from New Zealand and Australian research groups too. The focus has drifted towards their own societies presumably for the reasons that ‘the frail bodies’ and ‘death and dying’ become the other. Indian scholarship, on the other hand, is yet to bring its attention to the life course of the weak and the sick in Indian society, either for cultural reasons where care and dying happened at home, or the need to reflect upon such issues have not yet been realized, or due to the fact that the study of health and well-being remains a topic at the periphery of the disciplines of sociology and anthropology.

With the transitions in family structures, an increasing burden of non-communicable diseases and the ever increasing migrant population trying to barely meet ends, especially in urban cities like Delhi, it becomes imperative to explore the role of palliative care. Living with a disease like cancer was observed to have social, emotional, spiritual and economic bearings on the idea of a dignified sustenance of human life. The stories from the field shall be throwing more light on the same. In turn, I use these experiences to understand the politics of care and dying. I focus on the social relationships as well as the practices of support, the idea of care based on obligation, attention, providing, receiving and performing to show that the forms of experiences known for a palliative care set up in the households in Delhi NCR may not always equate with the standard accounts of global palliative care-giving. The locally suited values contribute to the propagation and performance of PC. The interest therefore was toward locating suitable practices instead of going by the organization’s idea to accomplish good care and keep a check on bad care. I try to explore this notion of ‘suitability’ viz-a-viz care and dying, and the meaning it renders to the lives of the stakeholders, which is a heterogeneous group of care providers as well as patients, self-caring individuals, and survivors.

The process of ideation began by examining the people’s experiences with PC while witnessing the everyday lives of those who live with cancer as well as those who care for them. These boundaries often get blurred and I do not attempt to steer clear of the blurred realities. Instead, I try to argue for the dismantling of the defined stereotypes within the extant palliative care practices. For instance, the meaning of care changes drastically when a team member allows the patient in her last days to smoke. How do the stakeholders come to terms with such transitions and what kind of impact it has on their relationships is addressed in this work. PC not only remained the object of enquiry, though that’s how it began, but turned out to be a periscope to delve deeper into the human lives enmeshed in realms of care and the social aspects of cancer, disease, dying and death. The central idea of the thesis is to explore the routine practices of care people engage with while living with the disease of cancer. The thesis has been a descriptive as well as an analytical exercise. The field interactions and observations led to a string of questions, i.e., do we have a social character of cancer and what is it like and how does it attribute to people's understanding of the disease and care? Also, how do individuals and society come up with means and ways to extend support to the sick and dying and what are the trials and tribulations they may undergo while seeking or rendering this kind of support and, most importantly, what are the experiences of people living with cancer? What does palliative care mean to people? In addition, I am trying to explore the plausibility of theorisation of the wider meaning of care while simultaneously tracing the social-ness of dying at individual as well as institutional levels. Since it is an exercise in ethnography, I have also presented my negotiations with the transitory nature of field. These engagements, though reflexive in nature, address the perils and promises of reflexivity.

The thesis is about people living with cancer and many of those who are in their last days struggling with advanced cancers. Structurally, it comprises of an introduction and a conclusion along with four chapters which have been written keeping in mind the trajectory of events in the field, therefore, not only the narrative is shaped within the period of the 'diagnosis, the prognosis, the event of death and after it', but each chapter also acts as prelude to the following one. For the convenience of dealing with each ingredient of the title, the chapters have been written in this fashion. In the title, dying comes before care for the specific reason that the research work is on cancer and majority of the families that I visited with the teams were nursing a member with advanced cancer where many of the stories could not be recorded extensively as the patient passed away too early after the initial diagnosis. The care that was being practiced, in the first place, acquired its meaning because of the process of dying i.e. the event of dying resulted in care practices. Also, keeping in mind the prevalent notion of cancer being synonymous to death, the title acknowledges the idea of death at the beginning of the diagnosis of the disease of cancer and the way care in its multiple forms, for instance clinical and domestic, brings about transitions in the understanding of this pre-conceived notion.

The introduction accounts for a broader summary of the entire thesis without going into detail explanations. It only presents a passing reference to the foundations of the theoretical understanding for the subsequent chapters as I discuss the relevant literature in great detail later. The first chapter, following this introduction is titled as, *'The field: of palliative care, from palliative care'*. It is critical description of anthropological understanding of the concepts of field, fieldwork and ethnography as well as a reflexive account of the methodological challenges met in the field which is followed by a descriptive account of the structure of the field and a critical analysis of the practice of palliative care based on the observations in the field. The next chapter, *'Understanding care'* is an analytical as well as conceptual engagement with the concept of care based on a close observation of intimate care practices. The subsequent chapter, *'Living, dying and palliative care: experiencing living while dying and the understanding of death'* elucidates the social understanding of the lives of the dying. This if followed by the last chapter, *'Reflections on cancer and the related casualties: an ending'* which summarizes the preceding chapters through a social narrative of cancer and ends with an account of reflections over the loss.

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1. INTRODUCTION

This is a dissertation about living and dying with cancer. It is an ethnographic venture drawing from a year and half long fieldwork with a palliative care organization providing free of cost supportive care to people living with cancer in the rural and urban pockets of Delhi NCR (National Capital Region). Everyday interactions in the form participant observation, conversations as well as unstructured and semi-structured interviews (in certain cases audio-recorded) are used for data collection.

With an increased precedence of cancer and other non-communicable disease leading to chronic disabilities and dependence as well as a growing number of elderly populations, care is emerging as one of the central issues of contemporary times. The literature from various locations in the west demonstrates an increased urgency to understand the care needs by taking cognizance of the demographic changes along with the epidemiological and global economic transitions. Within the Indian context, the issue of care does not garner ample attention and the obligation of physical care rests on the families especially the women and in many cases on the young children and the elderly too. If understood within this context, the work explores the roles and responsibilities of the patients and the families in the wake of intimate care needs and throws light upon the palliative care interventions carried out to support them. The home based care opens avenues for closer interactions between the external professional expertise and domestic knowledge and practices. The work examines the confluence of these two spheres and the emergent meanings and modalities of care.

In this thesis, I rely on the intimate experiences of care to explore the politics of infirmity, long term care and dying. This leads to an understanding of multiple aspects of care, notion of choice and the art of communication amidst a network of social relationships. I show the forms of local iterations that emerge in this setting and how this understanding may not equate with its global counterparts in the field of palliative care. While the organization promotes supportive care with a biomedical as well as liberal humanitarian perspective, the field reality differs as the families and patients execute agency to negotiate their choices. To elaborate this phenomenon, I make use of the idea of suitability instead of the defunct binaries of good and bad to lay down a narrative that is more complex to decipher. In addition, I draw attention to the new ideals of care at the individual as well as institutional levels.

What is palliative care?

A question that has been asked by many since I decided to conduct an ethnographic study in this area. The Institute for Palliative Medicine at Calicut in Kerala, which is also the first WHO collaborative centre for community participation in palliative care and long term care within the developing world, defines palliative care on its website[1] as

> "Palliative Care is the active total care of patients with incurable diseases. Palliative care responds to physical, psychological, social and spiritual needs of the patients and their families and extends if necessary to support the family in bereavement. It is patient centered, and not disease-focused."

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[1] http://www.instituteofpalliativemedicine.org/palliativecare.php

2 http://www.who.int/cancer/palliative/definition/en

According to the World Health Organization[2],

> "Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care provides relief from pain and other distressing symptoms and offers a support system to help patients live as actively as possible until death. Palliative care also offers support to help the family cope during the patient's illness and in their own bereavement."

In other words, palliative care is an interdisciplinary practice which combines knowledge from social sciences and medical sciences to improve the quality of life.

In one of the visits, a doctor from the team shared her initial dilemma of working in a palliative care setting and feeling that the frequent deaths in the field challenged the basic premise of medical practice which acknowledges 'saving life' or 'curing' a disease as its ultimate achievement. In such a situation, a disease like advanced cancer baffles the practitioners of medicine when death appears as a failure[2] of their acquired knowledge. In common parlance, palliative care is understood as providing care instead of cure.

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[2] Clark (2004, 40) refers to 19th century as the period where hospitals started developing at a rapid speed but there was no time to show concern for those at the end of life whose condition was beyond cure and in such a situation, as per the author, death became an 'embarrassment in the new medical citadels and so it was outside the 'mainstream' of medical perspective' that philanthropic endeavours led to creation of institutions like hospices. Hence, the author mentions that the beginning of 19th century was marked by new developments in the care of dying people which were mostly led by women (ibid. 41). Initiatives for improving care actually began to gain popularity in early 60s' especially in Britain and USA where the attention focused on neglect of terminally ill and a reaction to medicalization of death emerged as two respective concerns (ibid. 45).

However, the proponents of palliative care emphasize its significance from the time of diagnosis of any chronic life limiting or life-threatening condition. It is carried by a multi-disciplinary team which focuses on counseling the family members and the patient, providing palliation using pain drugs and most importantly by improving the quality of life of the terminally ill. It is not used to delay the progression of death or hasten it by any means (Clark 2000b). Instead it is promoted as an effort to add quality of life to the remaining days by alleviating the pain and seek a dignified death[3].

Modern hospice movement which began in the west earmarks the origin of palliative care. The development of terminal care and hospices dates back to fifties when many physicians, social workers and psychiatrists began to develop an interest in providing care to the 'terminally ill' (Clark 2000a:52). Dame Cicely Saunders was amongst the first leading names in United Kingdom to push the envelope further and open the first hospice, St. Christopher's Hospice, in 1967 (ibid.). It was during (in 1973) a visit to this hospice that the term palliative care was first presented by a Canadian oncologist Balfour Mount in 1974 in the context of a newly initiated hospital-based service. Palliative care began as an initiative to alleviate the sufferings of cancer patients who faced immense pain and other bodily distortions, as a result of invasive surgical procedures, in the dearth of symptomatic relief management programmes (Clark 1997). The term symbolized the expanding horizons of healthcare trying to accommodate a humanistic orientation focusing more on patient choices within the extant paternalistic framework (ibid:905).

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[3] The organization I am associated with works by the maxim, 'we can't add days to their life but we can add life to their days' (as mentioned on their website). The available literature on palliative care and associated issues extensively show that the 'quality of life in the end days' and a 'dignified death' are two basic premises which are advocated by the supporters and practitioners of palliative care.

Ivan Illich (1975) presented a critique of medicalization during the same period which highlighted the impact of modern medicine on the lives of patients by showing its influence using the death statistics, it was an attack on the medicalization of dying and palliative care emerged as a leeway with an interdisciplinary focus.

During the last quarter of twentieth century, there has been a significant growth in the developed world with regard to the availability and accessibility of palliative care services whereas the developing world is still trying to cope with many pressing social problems and a different set of health care priorities which focus more on infectious diseases (Clark 2004), leaving those about to die in limbo. It is imperative to trace the historical development of palliative care in India and locate the present status of this field in the country.

A brief history of palliative care development in India

In case of India, the historical existence of modes of cure and care, well within the limits of available resources and the needs suiting the local sentiments, was always present. One such systematized model of care has existed in Benaras[4], a place in India where people go for religious reasons to die and are accompanied by their family members who take care of them while awaiting their death [(Rhymes 1996) and (Cohen, 2002)]. Its sustenance is largely contingent upon the role of family members of the patient. During their last days, they seek solace and try to accept dying as an intrinsic part of their life based on cosmological understanding of the world.

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[4] For a similar instance in the west, one can refer to Clark (2004) for a detailed account of non – medicalized model (guided by religious and moral values) of care (in the form of homes) for the terminally ill in Europe dating back to late 18th century.

According to Shanmugasundaram and O'Connor (2009), in 2005 there were hospice/palliative care services, either existing or under development, in about 100 countries around the world with 7000 to 8000 palliative care initiatives including community based teams, inpatient units, and day care centre. The distribution of these services is however, heavily tilted toward western countries. Only about 6% of all palliative care services are located in Asia and Africa, the regions where the majority of the world's population lives and dies. As per the authors (ibid.81), the data on developing countries suggests that even in those countries where palliative care services exist, the coverage is limited and palliative care is not on the health agenda of their governments as a public health problem. This limits the ability of palliative care services to reach the populations that need them the most.

Apparently, the public health policy in India has promoted numerous measures to keep infectious diseases in control which has resulted in initiatives towards improved sanitation and drinking water supply (Rajagopala and Kumar 1999). Also, in an attempt to generate awareness and increase participation in vaccination and immunization programs, Indian government has made an active use of print and electronic media as well as of volunteers and civil societies, Pulse Polio Program being a case in point. On the contrary, much lesser attention is paid to the increasing burden on non-communicable diseases. They also suggest an increasing burden of non-communicable diseases like cancer especially amongst the ageing population.

Despite the increase in prevalence of cancer in India, which is often detected in the advanced stage(Shanmugasundaram and O'Connor 2006: 242), and the cases of HIV positive population, out of which many will be progressing towards terminal AIDS sooner or later, fewer measures have been taken towards providing palliative care to the sufferers (McDermott et al. 2008). According to Shanmugasundaram and O’Connor (2006:242), the government bodies with the assistance of non-profit organizations often conduct cancer care programs but these programs allegedly have no provision as far as palliative care services are concerned. The lack of availability of palliative care services makes it difficult for the patients and their families to have a timely access to it.

The knowledge already exists about how to improve the quality of life of those who are dying but it is not widely practiced (Shanmugsundaram and O’Connor 2009) in developing countries due to an increased concern to address issues of poverty and lack of basic needs (food, clothes, and clean water), lack of resources and inadequate health care infrastructure (ibid.2009:79). In case of India, with two-third of its population inhabiting the rural areas, problems of illiteracy, poverty, lack of awareness regarding the types of available health care challenge the progress of palliative care (Gielen et al., 2011). There are, however, three specific barriers to palliative care implementation that are generally accepted as the major impediments: lack of government commitment, opioid availability, and limited education (Clark 2007, 2009)[5]. As a striking contrast to the above arguments, Kerala is the only state in India which has emulated the palliative care model in all its districts and this has been possible due to the active involvement of non-profit organizations in the region which work towards providing community-based hospice and palliative care services (Clark 2007) which hints towards potential possibilities for replication in other parts of the country. In 2013, Tamil Nadu planned to incorporate the

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[5] The authors cite Foley K. (2000). Dismantling the barriers: providing palliative and pain care. JAMA. 2000 Jan 5;283(1):115.

district-wise palliative care service delivery into their health system in the year.

According to the Human Rights Watch Report (2009), in India the development of palliative care is at a nascent stage and the situation still remains grave given that, as per the WHO estimate, almost a million people are diagnosed with cancer every year and at least 800,000 of them are incurable at the time of diagnosis. The report also claims an absolute absence of any discussion on palliative care in the under-graduate medical curricula. The absence of palliative care services in many parts of the country is attributed to the stringent state-specific drug policies (especially morphine, of which India is the largest exporter). Dr. MR Rajagopala and Dr. Suresh Kumar (1999) created the first palliative care service centre in India in 1986, Pain and Palliative Care Society (PPCS) at Calicut, Kerala. According to Rajagopala and Kumar (1999), the handful of palliative care services functioning in the country since then has been inspired by the western model. They blame lack of enthusiasm in the government machinery as the key reason for an extremely slow development of these services in India. In their study, McDermott et al. (2008:585-586) identified 138 organizations providing hospice and palliative care in 16 states and union territories while no such provision could be found in the remaining 19 states, which implies many areas across the country have no provision of palliative care for cancer patients. McDermott et al. (2008) describe the successful development of palliative care services in three states of India namely, Kerala, New Delhi and Assam. This study considers New Delhi as the site for research in order to understand and critically analyze the delivery of palliative care services in a metropolitan set-up where I take into account the experiences of patients and their families to understand the role of palliative care in their lives.

The present palliative care organization in New Delhi offers its services to cancer patients in Delhi and NCR. It was started in 1997 under the efforts of the lady who survived Hodgkin’s lymphoma and took inspiration from her own illness experience to come up with this initiative. The organization has fifteen teams (during the period of my fieldwork), with each team comprising of one doctor, two nurses and two counselors. These teams visit patients across Delhi and its neighboring areas to offer home-based palliative care services to the patients and their families.

Over the years, a few more organizations providing palliative care have surfaced in Delhi but the home-care program of the organisation distinguishes itself as the oldest and one of its kind projects. The pain clinic at IRCH AIIMS and the organization have collaborated so as to have a follow up of the patients’ prognosis. Otherwise, the hospitals along with Delhi state hospitals had no active palliative care units till the time I was engaged in my field work. The public health understanding of palliative care lays emphasis on the service delivery models and the role of caregivers. This work tries to break away from this discourse and explore palliative care from an anthropological perspective.

Theoretical Underpinnings

Disciplines of sociology and anthropology derive their basis of existence from social interactions between individual and the community. The interaction is not merely through an exchange of words but through unspoken gestures/signs and symbols as well. Language plays a key role in interaction and goes beyond speech. Both spoken and tacit gestures result in an understanding between the actors who further make use of it to enable as well as comprehend the world they try to live in and make sense of their surroundings. An anthropologist observes and analyses the very understanding and turns it into a written account. The entire process of observation and documentation is not to persuade or dissuade a phenomenon but to explore, understand and chronicle it. It is an exercise in producing and reproducing stories of the world around us. A story rooted in socio-cultural experiences is important to make sense of the present. Also, I refer to my findings as stories with the awareness that stories are the basis cement for developing theories or may be all theories are stories in their basic essence for they help us understand reasons behind the occurrences of events. I call my findings stories for the reason that stories are elaborate narrative depictions accounting for multiple aspects in the routine lives of the patients and survivors instead of segregated findings based only on interviews and statistics.

> “Strong theory, in our view, delves into underlying processes so as to understand the systematic reasons for a particular occurrence or non-occurrence. It often burrows deeply into micro- processes, laterally into neighbouring concepts, or in an upwards direction, tying itself to broader social phenomenon. It can have implications that we have not seen with our naked (or theoretically unassisted) eye. It may have implications that run counter to common sense. As Weick (1995) puts it succinctly. A good theory explains, predicts and delights” (Sutton and Staw 1995: 378)

I do not propose a theory here per se, but ethnographic exercise leads us to social theories as it basis its analysis on the understanding of causal phenomenon. Stanley (1990:617-627) critiques the unilinear and rigid understanding of ethnography as a set of theories and charts an illustration of ethnography that exists as a method as well as an epistemology. She cites the limitations of the description attributing it to our attempts to turn the research experience into a text that ‘satisfies the concerns, standards and requirements of our academic peers and superiors’ (ibid.624). She finds any ethnographic description incomplete for the reasons that it is about the researched and an interpretation on the part of the ethnographer to cater to academic interests more than the interests of those in the field. Taking cognizance of this approach, I share my reflections in the next chapter on the exercise of ethnography before beginning with the description of the field.

The British as well as American anthropology has a long sustained interest in the exploration of care. The shamanistic practices, witchcraft and the understanding of local aetiologies are a way to understand what constitutes care practices in other cultures. Off lately the scholars from the STS school have come up with the theorization of care practices too. Good and Good (1993) critique the notion of care perceived in literature of philosophy, feminist ethics, nursing and medicine calling it one sided as it subscribes to emotional convictions and the ideals of attention and concern. My work argues to look beyond the ideals and explore the provisions that create these care practices. Further ahead, in the chapters I discuss the anthropological works that ask similar questions related to care in their distinct contexts. If care is solely understood as a process of giving it mitigates variability of contexts and positions.

Therefore, the basic problematic of this work lies in exploring and addressing the issue of care as a universal feature of human societies. My work draws from the principles of interpretive anthropology as well as critical medical anthropology to develop an understanding of the physical, emotional and moral aspects of care work that involves physically enduring practices to look after frail and dependent bodies. I examine the practices of meaning making and the lived experience, values and choices that guide people’s actions and posit questions associated with a broader understanding of the constituents of health and wellbeing as components of human right. Through this study, I propose an inquiry into a macro level understanding of well- being till the time of death. What do we understand by the overlap of external and internal models of intervention and what implications do these have on the lives of people suffering from cancer? This exploration can help us in understanding similar negotiations in the face of life limiting or life threatening conditions.

Chapter overview

The second chapter titled ‘The field: of palliative care, from palliative care’ is a critical analysis of the ethnographic practice and the concept of the field. The chapter is a reflexive account of my entry into the field, the engagements and negotiations and lastly, the process of distancing from the field. The chapter incorporates details of the field and from the field. What constitutes the field? The idea is to address the fluidity of the temporal boundaries of the field, which could be a body, a home or even the vehicle we used to travel in, as well as to provide a critique of the notion of objectivity of fieldwork. I address the issue of reflexivity and the methodological challenges of conducting fieldwork in the intimate settings of care for the debilitating and dying. The chapter also reflects upon the changing conceptualisation of ethnographic practice within the field of anthropology and the questions raised by the interplay of power between the researcher and the researched. As a woman ethnographer, it becomes imperative to reflect upon role of gender in the field and the subsequent insights. This chapter is a methodological description of my entry into the field. The exploration of the meaning of the term palliative care as understood in the field begins in this chapter. With no exact Hindi translation of the word, how is this term introduced in the field and what meanings do people derive from the term and what kind of implications does this understanding lead us to. For instance, the team members were often heard introducing their services as *sewa* (an act of philanthropy/guided by altruistic intent). I bring insights from the field reflecting upon the notion of *sewa* as palliative care. The chapter further explores the notion of palliative care amongst those who deliver it that is the team members.

For instance, the chapter throws light on the functioning of the organization and how care is practiced and perceived by the members and the employees of the organization. What kind of bearing do the field encounters have on the formal care givers with regard to their understanding of cancer and palliative care? I also discuss the way palliative care is understood as per the organization’s protocols and the way individual formal caregivers maneuvered the practice in the field and the newer meanings thus attributed to the local understanding of palliative care. This understanding of palliative care is not to be understood sans cancer. The disease and its manifestations in the field were decisive in the way palliative care was perceived by the providers. The chapter, therefore, brings their perceived concerns regarding cancer; it’s diagnostic as well as care practices, and their reflection of the dying. These observations help us in understanding the dilemma between the experiential knowledge gained through witnessing the patients in the field and the knowledge acquired through medical and para-medical training and how the formal care givers address this dilemma. This also brings us to the question of euthanasia and the way various team members addressed it based on their own understanding of euthanasia per se. Historically, palliative care has emerged with the hospice movement against euthanasia, therefore, it was interesting to observe contested narratives from the providers. The chapter raises these conflicted issues and provides a socio-cultural narrative for the emerging dilemma.

The third chapter, 'Understanding care' throws light on the meaning making process of the patients and families who engage in palliative care. What significance does it hold for them and how is this significance explained? Many practices like rendering support for pain management, being there during a person's last hours, countering fears related to the disease, preparing the family for the death, addressing difficult questions with emotional, spiritual and socio-cultural bearings, and eating at the households, were seen to establish strong bonds between the team and the families. How can these associations be understood within a sociological framework? The chapter examines the linkages between mortality and social relationships as well as engages with the issue of morality to understand the nuances of social relationships formed during palliative care delivery. The central idea of this chapter, therefore, is to address the meaning of palliative care for its providers and receivers as well as the relevance it held in terms of establishing social bonding and the role it played in developing an understanding toward care and dying due to cancer. This chapter further weaves these observations to attempt a conceptual analysis of care. The chapter uses palliative care as a tool to probe the wider ambit of care. This involves incorporating activities which may not be considered as care through the paradigm of palliative care or even health care but might hold relevance for the receiver. The idea is to look for multiple portrayals of care and how limiting it to a particular set of rules and definitions often caters to a parochial understanding of the term. The chapter is not trying to come up with a cultural category of care but a category which reflects our existence as human beings capable to innovate means of support. I question and critique the possibility as well as plausibility of a conceptual theorization of this term. In addition, the palliative care practices witnessed in the field were accomplished with the support of the families. Therefore, the role of family as a basic unit of care is explored and further argued. I have tried to demonstrate the complexities of understanding care through the binary paradigms of good versus bad, provider versus recipient and self versus the other. For instance, the binary of the recipient and the provider is fuzzy when I attempt to explore the larger meaning of 'care' as the caregivers, the family and the team members, were in need of a particular kind of care, if not palliative care per se then a kind of support emerging out of it. The work addresses this fuzziness not only in an attempt to derive interpretations and meanings but to grasp the processes which create this overlap and also to understand the consequences of such an overlapping. This chapter critically engages with the works of Annemarie Mol and Arthur Kleinman. Care here can be understood in terms of materiality, food, spiritual practices, sticking to a regime etc. This chapter, thus, addresses a care complex i.e. I talk about the broader categories of care, which I gained access through palliative care, and the implications of this extension on our understanding of care and its role in social life/ relationships.

The fourth chapter titled as, ‘Living, dying and palliative care: experiencing living while dying and the understanding of death’ is about exploring the perspectives of the people living with progressed disease who are aware of their dying as well as the families who prepare for the event of death and later, reflect upon their loss. The field insights are to attempt a narrative of dying as a particular form of social life given the unpredictable character of death. This chapter is also a means to develop understanding of death in a city like Delhi where people from different cultural milieus live together. This is compared to the western understanding of death to look for overlaps and distinctions. The purpose of this comparison is to add to a more holistic account of death and dying instead of coming up with an alternate cultural narrative. The culturally deterministic model of explication is more suited to account for the practices carried out during mourning, funerals and burials. But if one needs to grasp dying as a particular form of social life, cultural explanation can be one of the components but barely a defining one. The chapter discusses the field insights to elucidate dying as a process and the kind of social bearing it has on people who are aware of their wait for death. The notion of karma as well as the moral code of death are discussed so as to grasp the process of meaning making. How death is addressed in the field is also pertinent to the understanding of the local worlds of people. In addition, the chapter accounts for issues close to the lives of people in their end days and how these negotiations were raised and discussed, be it the about the place of death or acceptance of death per se. The chapter puts forward a critical analysis of the terms used within the field of palliative care, such as end-of-life care, terminal illness, quality of life presented from a biomedical prism on the basis of the field findings which support a larger contribution of the agencies involved in care delivery while lying outside the biomedical ambit. These descriptive accounts are to look into the societal understanding of death and dying, palliative care being part of the very social fabric. The critical analysis of these events depicts a focus on the causal agencies of death instead of death owing up to its universal and ubiquitous character in the face of loss. A comparison between death per se and death due to cancer explains this stance more clearly. This chapter delves into the works of Allan Kellehear and Glennys Howrath in order to come up with a narrative on the social life of dying. I also discuss the role of communication in this chapter. Do doctors really discuss the tradeoffs? The initial idea of medical sciences was to relieve suffering; it still lurks in the hospital corners. But with the advent of health care 'industry', the idea of care is lost.

The thesis argues for palliative care as an embedded practice and not a specialty on its own within the biomedicine. The premises on which any health system lays its foundations is the notion of well-being and a practice which cannot accommodate care into its routine functioning is not completely capable of wellbeing. For instance, in the field, while on our way to a patient's house the nurse received a frantic phone call from another patient whose 'old' mother was in one of the very renowned hospital of Delhi. The doctors had expressed their helplessness and asked him to move his mother back to the house. But he had concerns and questions. His mother was kept in the intensive care unit of the hospital for ten days supported by a ventilator. He had already spent a huge amount (running into six figures) for what was his hard earned saving. He used to work as a personal driver and has not been able to go to work. He asked the nurse for advice and the nurse told him empathetically that they had already informed him. He was angry with the hospital which kept his mother for ten days prolonging her pain and suffering and yet not being able to resolve it in the end. He said he has been ‘duped’. He confessed his fear of taking away the ventilator as it would stop his mother from breathing. He was wailing saying that his mother couldn’t express her last wishes to him. The nurse told him that his mother’s breathing is going to stop for the reasons that she is being artificially supported, “whatever breath is left will be out with a harsh vibratory sound.” Meanwhile, rest of us in the car were patiently listening to the entire conversation. The nurse wanted to know if he had anyone for company. His brother from the native village was by his side. The nurse insisted on talking to the brother and asked him to do as the doctors say suggesting him that she might have some time to make it to home and see everyone before leaving. She told the brother to look for a provision of oxygen cylinder in the house or they could pick one from the nearby regional office of the organization and get it filled. Apparently, the brother understood the situation and the conversation ended. Next morning in the office we were told that the old lady was shifted to her home by evening and she took her last breath this morning. She was unconscious and the breathing gradually slowed down. This incident was not one of its kinds in the field. Many families were informed earlier by the team members about the symptoms in the last hours. I had been witness to so many conversations where the families were told not to immediately rush the patient to the hospital but to call a nearby doctor and seek advice and talk to the team over the phone. In many cases, the team was already at home when the patient was to die and the family was suggested to follow any relevant last rituals before death. For instance, in a Hindu family the patient was given drops of *Gangajal* (water from the river Ganges) with *tulsi* (basil) leaf and the person was lifted from the bed and kept on the floor. In this case, however, we are not aware of his conversations with the doctors about his mother. The team shares that he was suggested not to take his mother to the hospital. But this reflects our unpreparedness as well as denial of death in many ways as well as the problem of choice. When I say 'our' it implies the larger world. This chapter discusses the possibility of communication which still may never prepare us for death but enable us to make choices before slipping into the alley.

The last chapter, titled 'Reflections on cancer and the related casualties: Towards an ending' is a narrative summary around the disease of cancer in order to throw light on the understanding of the previously discussed themes. The chapter addresses the issue of grief and bereavement and its role in the lives of other family members. A qualitative study of this nature raises a few questions regarding the essence of health care system comprising of medical doctors, hospitals, pharmaceuticals and as well as the state. Medical sciences have pushed the boundaries and innovated ways to control, treat and address diseases, disability and the suffering. But even then is bound by the limits of death. The inevitability of death is nature's way to show us our limited control. This makes us question how ready we are to acknowledge these limits and work towards acknowledging and pursuing the dying person's idea of spending last days of life. The chapter is a reflective analysis based on such an understanding.

Relevance of the Study

A recent news headline[6] in a national daily states that Indian health ministry is going to inform the Supreme Court, the highest appellate court of India, that an amount of Rs 636 crore 'National Programme on Palliative Care' has been finalized to make end stage life of patients suffering from cancer and HIV as well as the elderly population of the country as pain free as possible. In present times, the current study becomes all the more relevant as it can provide a medium to understand the experiences of families and patients who have been involved with palliative care services.

Also, the findings of the present study may be used to locate the key factors which might make it possible for palliative care services to reach across India. The reasons for the failure of implementation and execution of these factors can be addressed through this work. In addition, a relative lack of research in this area within the field of sociology of medicine and medical anthropology in India makes it imperative to have a detailed ethnographic account, thereby contributing to the socio-cultural understanding of individuals' and their families' experiences towards palliative care. Mol (2008) suggests that gathering knowledge is not a matter of providing better maps *of* reality, but of crafting more bearable ways of living *with*, or *in* reality" (ibid.46 emphasis mine). The

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[6] http://articles.timesofindia.indiatimes.com/2012-11-05/india/34926076_1_palliative-care-centres-health-ministry

present study is a modest attempt to explore those ways and contribute to the understanding of concepts like death and care within sociology. This work is locates the care in multiple aspects of our lives and explores its plausibility and potentiality as an analytical concept. I do so by examining the interactions with palliative care as well as using it as a lens to explore larger meaning of care by exploring the following question:

How cancer is perceived in popular understanding as well as by people who are touched by it, as patients, as family and as practitioners? What role do these perceptions play in locating the position of care as a practice? How is home-based palliative care understood by the patient and the family and what is the local understanding of palliative care? How death as 'anticipated outcome' is understood within the family? Considering the presence of a terminal illness, what are the transitions observed by the patients and their families in their day-to-day lives? This work does not answer these questions but provides us with a reflective account to understand the stakes while enabling us to come up with more questions related to our own existence.

2. The field: Of palliative care, from palliative care

> “Since fieldwork is increasingly the single constituent element of the anthropological tradition used to mark and police the boundaries of the discipline, it is impossible to rethink those boundaries or rework their contents without confronting the idea of "the field." "The field" of anthropology and "the field" of "fieldwork" are thus politically and epistemologically intertwined; to think critically about one requires a readiness to question the other. Exploring the possibilities and limitations of the idea of "the field" thus carries with it the opportunity-or, depending on one's point of view, the risk-of opening to question the meaning of our own professional and intellectual identities as anthropologists.” (Gupta and Ferguson 1996:3)

Fieldwork in Anthropology

The present study draws from a long term fieldwork which uses observation, conversations, semi structured-interviews and interview guides in some of the cases. In this study, quasi- observation would be a better choice of the work for the reasons that my involvement in the field was neither purely participatory nor non-participatory in nature. Srinivas et al. (2002:4) rule out the possibility of non-participant observation in a long term fieldwork but as per the authors it is relevant to have a role in the field which was not possible for me especially in a setting like this, where team members visited homes in the capacity of legitimate care givers.

> "The non-availability of roles may heighten the fieldworker's problem of legitimacy. He may be considered an unwelcome intruder, or, worse still, a simple idler." (ibid. 4)

With the changed terrain of ethnography and fieldwork (Faubion and Marcus 2009), such assumptions do not form a yardstick. I call this work ethnography of palliative services and not the palliative centre for multiple reasons. Firstly, this study has been carried out in the field, mainly at the patient homes, where different teams from an organization deliver care. Many anthropologists over the years have illustrated through their writings how the fieldwork was carried out, even if the conditions were hostile or indifferent as in the case of Geertz (1973) when he participated in hiding the information from the police about the popular Balinese cock fights. Entry into the field is a challenge in its own way. As the organization granted me permission to accompany the teams for regular home care visits, the larger responsibility was to be accepted not only by the teams but by the families and the patients. The teams try to explain the nature of their work as I gradually tried to initiate conversations in the household. Also, after attending the counseling course I came to know about the protocol of staying quiet in the families and let the teams do the talking. Mostly, the visitors, like me, who accompany the teams are asked to stay quiet as the entire atmosphere is often emotionally charged, people have serious health concerns and an outsiders interaction may not be welcome. The teams would always introduce me as we entered the household but for the larger part I would observe the interactions, go through the patient files to know more about the patient history and take note of the kind of interventions that had been made since the time of diagnosis. This gave me ample time to observe and chart a history of patients and often their equation with their family members. As the visits became more frequent, the families were used to my presence. Many families began to consider me as a member of the team when the teams steer cleared such doubts and told them, ‘she is with us for a few months’. Still the families began to discuss patient issues with me and the teams accepted it. I would roll down the question to the respective expert and engage in more general parts of the conversation. It was about consoling a crying family member or hugging a patient, patting her hand. Some of such gestures became a part of my interactions due to my experience with the counseling course whereas in other cases, I picked up from the teams. Eating and greeting were two key gestures that helped in developing proximity with the patients and the families. Indian households often have a huge fascination with people with relatively lighter complexions and I found many families telling me how they like talking to me because ‘you look good, have a clear complexion (“*rang saaf hai*”). The feminist in me would cringe hearing such statements which were assumed to be spoken in a good gesture, as a ‘complement’, but I found myself incapable to correct such a bias on a frequent basis and accepted it with a lame smile. This in certain cases extended beyond the so-called appreciation for looks and came up in the form of marriage proposals, as the teams would later inform me laughing it off. The teams shared my marital status but the fondness never receded. I, nevertheless, used this fondness for my own research purposes. Other than this, the patients’ especially young women opened up easily for the reason that they found me of their own age and as a married woman, able to relate to their domestic issues in their struggle with the disease. As many of them would say, ‘you must already know it' (*"aapko to pata hi hoga"*) while reflecting upon their domestic concerns. Similarly, middle aged and elderly patients often shared my resemblance with their own children and grand-children making it easier for them to communicate. Young men would shy, they kept the conversation restricted and the teams prodded them a lot on my behalf often presuming that I was researching the psychological as well as social immediacies in their lives. Nevertheless, such interactions remain a part of my data. The issue of access holds prime importance in ethnographic studies (Hammersley and Atkin 2007:42). It not only generates knowledge about the field but involves ethical boundaries of do and don't. Particularly in the field of health, such boundaries are seen as extremely relevant. In case of the present study, the organization allowed access in the field on lenient grounds with the only requisite of visiting the patients' houses with the team members after receiving documents related to my affiliation with the university and my purpose of research approved by my supervisor. In case any I needed to attend a particular meeting or function organized by the organization I used to take prior permission by getting in touch through phone, email or in person. I needed to communicate it to three key people in the organization and I was never denied. In this case, the access was layered. I needed access not only to the organization but to the patient homes and the teams' as well. The teams were very welcoming and acted as a personal network to gain access in certain families. In addition, I tried learning the language of the field by which I imply a whole genre of medical vocabulary in order to be able to converse with the doctors and the nurses as well as to enable myself to understand the prescriptions and medical reports of the patients. Apart from such small negotiations, I largely relied on my ability to strike informal conversations and establish a rapport with everyone in the field. The conversations varied from interests over books, politics, food, religion, clothes and much more. These conversations allowed the team members and the families to strike random conversations creating a comfort zone where we could later discuss the serious talk. Everyone was aware and open to talk about the disease and its implications and relations. It was through the everyday habits and customs, based on the Malinowski's (1922) understanding of the field; I could explore the various aspects of cancer, care and dying namely. The field work was an engrossing experience as well as an exhaustive one and this can be true for so many of the other researchers as well. Unlike the texts on field relations (Hammersly and Atkinson 2007:95) which suggest the hardships of the initial days, this fieldwork was fraught with challenging times in its last days. The growing proximity, emotionally charged farewells as well as a sense of saturation contributed to difficulties while leaving the field. The authors share multiple works where women as researchers are more vulnerable. There were similar challenges but they were equally distressing for other team members and staying in each others company helped us avoid any untoward event apart from listening to some depraved comments in our field interactions. I want to mention here the meaning of the term 'field' which extends beyond the geographical space. Field enacts itself through metrical and nonmaterial interactions as well as bodily afflictions too. I look at an exploratory meaning of the term field. In the later part of the chapter, I throw light on my entry into the field and the subsequent processes which shall count as fieldwork. My analysis across the chapters often indicated my own experiences with the field and I do not situate these experiences in a separate section instead incorporate them with the field findings.

> “Anthropological fieldwork has been represented as both a “scientific laboratory” and a personal “rite of passage”.” (Clifford 1995:109)

Field notes

Roger Sanjek (1990) brought together a compilation of field notes where different anthropologists presented their notions of field notes. For some it was a copious amount of work where as others barely referred to them yet in every case, field notes laid the foundation of fieldwork as first written recorded evidence of moments in the field. Rena Lederman (Wolf 1992) opines,

> “Field notes are dangerous. Observations are noted and written down in order to aid memory, but reading field notes can challenge memory. It threatens to return one to uncertainty about what was what; it acts against the sense of whole that one carries around in one’s head. Field notes can contradict the single anthropological voice we are all encouraged to adopt in our formal ethnographic writing at home by recording—however indirectly—the voice of the people we live with when doing fieldwork. (1990- 73)”

A fieldwork without field notes remains incomplete. Jackson (1990:8) mentions Simon Ottenberg’s idea of ‘head notes’ but field notes act as cues for head notes too. They are the pre-requisites for any data analysis and in certain cases the only form of available data apart from the memory, for instance, Srinivas’s monograph titled ‘The Remembered Village’ (1976).

In case of the present study, taking field notes while in the field was a regular ritual. Almost, twenty six years ago, Jean Jackson came up with an interesting analysis of anthropologists understanding of their field notes. Not much has changed over the years as I write in the capacity of a graduate student for her thesis. The training for field notes comes form short term fieldworks conducted in undergraduate days but largely by reading ethnographic accounts. The field notes comprise of the patient's name, particular words and reactions and the tone of such reactions as well as the concerns expressed in the visit and the interaction on the part of the teams. These notes were written in the form of jotting points, broken hints while paying heed to the conversation and later elaborated either after teams finished the fieldwork and we reached the office or in the van while on our way to other patients homes. There were times, when I was unable to take any jotters and would write the names of the patients visited and mention the key concern along with some cryptic images. As I reached home, writing them in a separate notebook with my own reflections was an on and off ritual for I reached home late, tired and unable to finish the day's write up. Holidays for festivals and Saturdays' and Sunday's provided me ample window, what Mead (1977:228-30) refers to as 'affluence' to reflect upon the missed exercises as well as resulted in something more, these notes have been an aid to the memory over the last two years. Once, for close to three weeks I did not get any time to write about the reflections and the experience was personally challenging. Writing field diary was cathartic[7] as the field was full of chaos with suffering, multiple deaths, ongoing audio-recordings with some patients, travelling everyday between 9:30 am to 5:30 pm, loads of talking, getting stuck in the traffic etc. But field was attractive too, for the prospect of meeting people and listening to their struggles was a humbling

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[7] For more on fieldnotes and the diaries as cathartic accounts read Sanjek (1990: 92- 121)

experience. But not all the data comes from field notes. As I revisit the field through the field diary and other recordings, almost after two years, this reminds me of Jackson's (1990) title 'I am a field-note' in a very figurative sense. Even in the last hours of tweaking the thesis, the newer meanings emerge for the reason that the idea of what I was doing keeps transforming. It was experientially rewarding for the reasons that the readings obtained in the form of secondary sources as well as the narratives from the field often took me into long periods of a contemplative slumber. The focus of the thesis was never absolutely thematic and on top of it the field findings over-flooded it making it challenging to begin writing. Reading ethnography accounts helped streamlining the clutter before coming up with one. Writing an ethnography involves what Clifford (1990: 58) explains through the cooking metaphor; "inscription (notes, not raw but slightly cooked or chopped prior to cooking), description (notes sautéed, ready for the later assassin of theoretical issues) and transcription (reheated leftovers?)". He (ibid: 58-59) hints the complexity of transcription by citing Talal Asad's essay on ethnography as polyphonic discourses.

> "The texts produced in the field are polyglot. They include large quantities of the local vernacular plus diverse pidgins, short hands, and language of translation, along with the language or languages of the ethnographer. The final "written up" ethnography smooths over the discursive mess—or richness— reflected in the field notes."

Despite the debates around field notes and the relative subjective character I found them one of the remote ways to be in touch with the field and the flaws with the method. Sanjek (1990:93) quotes Ottenberg's emphasis on the relevance of head notes. Head notes are a part of ethnographer's mental existence and their transitory understanding may lead to newer forms of analysis but field notes are a constant reminder of human errors without a scope for omissions. The field notes have a limiting character to them and head notes play a significant role in curtailing this limitation but often present us with the over imaginative pitfalls. I found it an essentialising exercise to remind myself that I, as a budding researcher, was working towards a write up instead of simply loitering in the field. Not only that, field notes acted as strong reminders of a day's events and a look at these notes later resulted into reinterpretation of the same event.

Confidentiality and Anonymity

Often the organization asked for a glimpse from what I used to write and it used to be a challenging exercise to be touchy about so many of the findings. In one such case, during visits with various teams, I was asked to write a comparative account of the way teams function. I am reminded of key information which is a part of my memory but no where in the field notes. This account generated a lot of discomfort but I was spared with an instruction of not sharing it with others. I was not interested in sharing the information with the organization as well citing privacy concerns of my informants—the team members as well as the staff from the organization, instead of the patients and the families as was presumed. Sticking to certain protocols is important and refusing to the organization's demands was difficult and I had to make a difficult choice. The patients were open to being photographed too but I decided to fade away the faces. The key interviewees in the organization gave their consent to use their names and the name of the organization too. I choose to use their names if deemed important but would like to hide them otherwise. In addition, I am allowed to disclose the name of the organization. I choose to hide rest of the names of people working for the organisation. The organisation allowed me access to patient houses and the data collection was carried out in their presence. In addition, I am going to use pseudonyms for the family members and the patients. I hide the gender identities of my informants where deemed essential. All the interviews were recorded with prior verbal consent.

During one of the Thursday meetings, the team presented a case of a female patient I was visiting. I had her audio-recordings, her pictures and other sensitive information. A day before the presentation, after returning from the field, the doctor asked me to bring all the data. I expressed my inability citing the reasons of confidentiality but he questioned the sense of privacy as the information was not hidden, I recorded everything in the presence of the team members and the data mattered for making their presentation more sensitive. This led to a heated argument and I was told that I will have to furnish the recordings in case the organization demands to know my nature of fieldwork. Would I refuse then? I shared that the data cannot be shared in its raw form; I can present a write up. After a heated debate, I talked to one of the key informants from the organization that holds an authorial position too and she assured me that no such information need be shared. I would like to make a mention that, across the thesis the names of people and places have been changed using pseudonyms and different locations within Delhi to hide the identities. In addition, the interviews or conversations were stopped if the informants expressed their discomfort with the process.

Interviewing and conversations

I audio-recorded nine caregivers (four men and five women) and twenty seven patients (eight men and twenty one women) after visiting them for over three months. They volunteered as well as willingly agreed to talk into a recorder. Some of them often laughed suggesting that I already knew a great deal about them. The idea behind these recording was to have their consolidated stories which could be further used while analyzing the data obtained through observing their interactions during regular visits. They were chosen on the basis of their willingness. In addition, I audio-recorded the interviews of the key informants in the organization and the regular conversations among the team members. I relied on note taking to keep up with the details of the conversations as well and clicked photographs in the field.

Writing Ethnography

The reflexive turn in ethnography marked it as an exercise embedded in writing. I relied on the two key texts, Writing Culture (Clifford and Marcus 1986) and its feminist criticism by Deborah Gordon and Ruth Behar (1995) to understand the arguments. Clifford (1986:1-26) stressed upon the exercise of writing a text, a discursive form and the false nature of cultural accounts. The two texts have encouraged a generation of anthropologists to incorporate identity politics in their compositions. Ruth Behar (1995) and Kirin Narayan (1995) have emphasized on the need for holistic accounts incorporating a sense of connection with the people and places we work with as well as inclusion of auto-ethnography. Colonial critique from Talal Asad's account led to the emergence of contexts where the power hierarchies between the researcher and the researched came to the fore. O'Railley (2005: 211) refers to a time when reflexivity was sacrosanct and nothing was spared from the reflexive eye. This was also referred to as a crisis in representation. Gradually, the boil settled down and a balanced approach has been pursued since, as the academic author regains some authority in the process of writing while being constantly attentive about how to write and what to write. The bunny hops from interpretive school to reflexive turn in anthropology to the newly orchestrated ontological turn, have all tried to lubricate the exercise of writing an anthropological account. The two very significant terms, anthropology and ethnography are often used inter-changeably and Tim Ingold (2011, 2014) blatantly rejects the use of this synonymy. He is of the opinion the discipline of anthropology should absolutely do away with ethnography. He perceives it as the only way to resurrect anthropology. He distinguishes between ethnography, fieldwork, participant observation and anthropology and finds participant observation to be closest to anthropology. Also, he perceives ethnography as a mere descriptive exercise whereas anthropology tends to be the more holistic correspondence. He stresses upon doing anthropology for the reasons that it involves attention, care and correspondence unlike ethnography that's less sexy, boring and 'a modish substitute of qualitative'. He critiques the over indulgence with the term 'ethnographic' for interviews, fieldworks, descriptive accounts and as a method and suggests the benefits of titillating sensual implications with the usage of the term turning any mundane encounter reverberating with the heartfelt intimacy.

> "Nothing has been more damaging to ethnography than its representation under the guise of the 'ethnographic method'. Of course, ethnography has its methods, but it is not a method. It is not, in other words, a set of formal procedural means designed to satisfy the ends of anthropological inquiry. It is a practice in its own right – a practice of verbal description. The accounts it yields, of other people's lives, are finished pieces of work, not raw materials for further anthropological analysis. But if ethnography is not a means to the end of anthropology, then neither is anthropology the servant of ethnography. To repeat, anthropology is an inquiry into the conditions and possibilities of human life in the world; it is not – as so many scholars in fields of literary criticism would have it – the study of how to write ethnography, or of the reflexive problematic of the shift from observation to description." (Ingold 2011:242)

SCA's series of critiques over his purported idea fetches scathing criticism from four eminent scholars. Andrew Shryock (2014) calls it a 'heady stuff' with no clear guidelines of how to come about it. Shryock critiques Ingold for his lack of interests in methods which are an amalgamation of personal travails and the process of data collection. Fieldwork and ethnography go hand in hand for him but he finds Ingold's position on the inadequacy of ethnographic empiricism a little problematic for the reason that Ingold barely mentions what this 'something' is? Shryock (2014) mocks Ingold as the high priest lacking ability to have a honest sex talk with the kids while the kids wonder how to, well, do it? Cook (2014) and Mac Dougall (2014) pose similar enquiry to Ingold's fascinating enterprise and suggest for keeping the ethnography within anthropology but trying to get better at everyday descriptions. Marcus (2014) is a relatively humble critic of Ingold's idea and reminds him about the operative character of ethnography in anthropology and stresses its role as the trade language of the discipline.

I was not aware of this debate when I began this study. Ingold's idea fascinated me and made sense for some of the right reasons. His idea of using the term 'ethnographic' to add sensual elements to anything we write is partly agreeable. This reminds me of Taylor (2003) who uses similar comparison for the art of storytelling. While Ingold limits his description to the phrase she extends it into the exercise of writing or narrating a story. There purposes are different, Ingold proposes a disjunction between anthropology and ethnography while Taylor simply argues against a writing style that is meant to please the audience. She critiques Fadiman's account of the Hmong child and insinuates her of writing a captivating account famous in the medical curriculum; doctors catch it and fell down! Criticality forms the basis of knowledge production. Ingold and Taylor propose these critiques but leave us half way without directing us, especially the young graduates, on what to do? The focus is on what shall not be done and for a student-researcher these articles sound captivating, on the verge of a new dawn in the discipline of anthropology yet in retrospection it appears too obscure. Taylor (2008) still offers a ray of hope and something familiar in the ethnographic enterprise. As for Ingold, it might take me long to explore his idea and with more voices supporting the position of ethnography within anthropology it becomes clearer that ethnography is to play a key role in the discipline for some more time despite the contestations. I shall be using the term 'ethnography', albeit cautiously.

Hence, the thesis remains ethnography. The discipline of anthropology has always claimed ethnography as a technique born within the discipline. The exercise of writing ethnographic accounts detailing the cultural practices and social institutions by exploring the everyday habits and customs have been a long interest of the discipline. The traditional anthropology was based on the need to locate theory and practice together. But with the advancements in the discipline, ethnography has been acknowledged in its own right. Gupta and Ferguson (1996:1) in their introduction mention,

> “Intellectually, ethnography has long ceased to be conceived of as "mere description," raw material for a natural science of human behaviour. Whether via the literary turn (from "thick description" to "writing culture") or the historic one (political economy and the turn to regional social history), main- stream social-cultural anthropology as practiced in leading departments in the United States and the United Kingdom has come to view ethnographic explication as a worthy and sufficient intellectual project in its own right.”

CanSupport: The NGO

An important confession before beginning with this chapter is that the study has been carried out in collaboration with CanSupport, an NGO, and yet the work isn’t similar to the researches carried out in the field of political sociology/anthropology or sociology of development where the NGOs’ become the primary object of enquiry. Anthropologists with their focus on the understanding of development and it’s association with state, emergence of civil society and voluntary organizations in developing[8] countries like

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[8] Anthropologists like Lewis (2014), Fisher(1997), Lewis(2004) and Said (1978) have respectively shown the frivolousness of such classifications based on the enmeshing of local and the global and its subsequent impact on the politics of NGOs’ and explained the binaries of developed and

India, Bangladesh and Brazil have carried out extensive work on ‘the third sector’. Unnithan and Heiytmeyer (2012) and Baviskar (2000), share their experiences of aversions cited for the usage of the term NGO and the subsequent preference given to terms like civil society organizations[9] or social action groups or social movements too. Baviskar (2000) mentions his concern on lack of detailed research in NGOs’ within the discipline of sociology. He cites instances where the work on NGOs’ has been less of a critical enquiry for the reasons that the interests of those in academia are often similar to those engaging in activism. In addition, he explains his displeasure with inadequate work on the internal functioning and administration of the NGOs’ as well as the prevailing structural hierarchies. While the above discussion focuses on the structure and politics of NGOs’, the current work makes use of NGO as an agency helping to closely look at the lives of people living with cancer while negotiating care and suffering externally as well as internally.

My work doesn’t intend to directly address the politics of the organizational structure. This is for the reason that the present research work began with the premise of developing an ethnographic understanding of disease, death and palliative care. This required spending long time with teams providing supportive care to the cancer patients and their families and therefore, conducting a fieldwork to understand the organizational

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developing as deriving their basis from colonial and post-colonial constructions of knowledge which distinguish between the west and the other thereby leading to a parallel discourse on international and local NGOs’. Lewis (2004) explains the mixing of external agencies and local traditions inspired by moral values leading to development of NGOs in South Asia.

[9] For more on civil society organizations, CSO, read Unnithan and Heiytmeyer (2012) where the authors share the field experiences in India with regard to the aversion of using the term NGO as it is often associated with the blooming groups floundering money in the name of development. Similarly, Baviskar (2000) cites multiple classifications and definitions of NGO. In order to steer clear from any such confusions, I would stick to the term NGO whenever the need arises as this is how the organization used to introduce itself without engaging with the politics of the term.

set up was beyond the interest and scope of this work. However, I suppose my day-to-day interactions with people working in this NGO might inadvertently throw some light on the structural exigencies of the organization. The organization provided me a platform to closely observe and explore the multiple manifestations of care when it is not market mediated and instead works through a system of moral values. During the process of exploring care, the team members expressed themselves and these expressions weren't limited to the care services they were delivering to others. The concerns ranged from dissatisfaction with the recent changes in the organizational structure to the extant professional hierarchies often emerging during the interactions between the doctors, nurses and counselors. The prevailing biases were not limited to the levels of professional competence based on experienced staff members and new entrants but often took shape of 'contemptuous aspersions'[10] due to personal differences.

Often the senior professionals observed that some of the team members were not very well equipped to address anxieties. The instances of individual limitations, however, attain validity only when compared and contrasted with the field observations of similar professionals in a different team. Within their region and in their own teams, they were the sole reference of their professional expertise rendered in the households at a point in time. During my visits with all the teams to different households their equations with the clients led to similar observations of satisfaction, discontent and the journey in between. There were no ideal types and neither should we expect for the reasons that the human

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[10] My usage of such harsh terms must not be attributed to a judgmental tone. In certain cases, the staff members were observed to indulge in sexist jokes and when encountered they would smile sheepishly. Many of the staff members, women, were often ridiculed for their dark complexion in the presence of others. Everyone laughed it off but some of them shared their displeasure in private. Those who were ridiculed were either women, new entrants or at a lower position as per the professional hierarchies established in the teams.

actions and intentions are incumbent on the perceptions of both the self and the other making it susceptible to unpredictable differences. I, therefore, do not attempt to perceive the acts of care as good or bad or subject the actions of caregivers to a similar analysis but to present the stories and leave it to the reader’s discretion. Also, since I didn’t spend equal amount of time with all the teams, some of the team visits might have an obligation to maintain uniformity in the patterns care delivery and communication. The uniformity can either be attributed to my presence as an outsider or can actually be a universal reality. Here, I attempt to write a prelude of the field to highlight the meaning of palliative care based on the very narratives of the multiple actors involved in its delivery. The idea behind beginning with this chapter is to gain an insight into the functioning of the organization as well as knowing the organization from within.

I, thus, divide this chapter into two sections. The first section includes an account of the origin of palliative care and the general history of its inception in India as well as a description of the structural and service related aspects of the organization whereas the second section is more complex as it tries to collate the multiple perspectives of the team members based on their field experiences and develop an understanding of palliative care from the practitioners perspective. The following section is an overview of the organization’s structure and programmes. It is an introduction to the ways the organization braces up itself before venturing out in the public. The second section is a descriptive account based on the field[11] interactions to present the cacophony of

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[11] I would like to add here that the work looks into a composite world of fields. There is no one field out there. The field is not a tangible space instead its location is contingent upon varied contexts under observation. For instance, while speaking about the disease, the tumor and the bodily symptoms become field; in the case of care, its the actions, the materials used, the home

differences in attitudes, practices and performances of the care providing teams, to get a glimpse into the lives of this social group.

A morning at a palliative care centre

Every day, the staff members arrive by half past nine and push the attendance button on the biometric device which reads their finger prints. Each centre has either two or three teams. In each team, the nurse plans for the route to be taken by selecting patients based on their respective levels of priority, by taking calls from the helpline office located at the head office where new patients get registered, by calling the selected patients to confirm if they shall be at home for the team's visit. Each team must visit a minimum of six (earlier the teams would visit five but from 2014 the number was increased) patients per day. The visits are decided based of the patient priority list (which is prepared on the basis of patient's needs), on the basis of the route map. Yet, six is not a fixed count as the teams often visit more patients if they receive distress phone calls from the families. In the meanwhile, some of the staff fills water required during the travel, the others complete the patient files from the visits a day before (if they could not fill them on the same day), and some try to prepare tea for which they contribute from their own pockets. The morning hustle-bustle is a good time to discuss patient histories from the previous day. Since each centre has one doctor (a few centres' do not have any doctor and doctors therefore, are shuffled, from other teams based on the requirement) and two to three teams, the doctor cannot accompany each team on an everyday basis, the team members share patient issues with each other, if and when required. The teams are provided with

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itself as well as the vehicle used for commuting to the patient houses, all of them define the field.

mobile phone facility and in case the need arises, the nurse from the field calls the doctors over the phone to discuss the case of individual patients. These phones keep buzzing 24x7 and in the morning too. Many visits are improvised on the basis of morning phone calls as well. It is over these phones, that patients and their families often share their physical discomforts. Also, many a times, the team calls at the house of a patient and hears about their demise. The team member on the phone conveys it to the other members usually in a way that it sounds routine to the ears and often 'pleasant' too. For instance,

> *Team member: X left. (X chala gaya)*
>
> *Reactions from others in the team: Oh! Thankfully. Good lord! (Shukr hai bhagwaan ka); OK..that's alright (Chalo theek hua).*

The reactions comprise of right amount of empathy and are, occasionally, casually spoken in a matter-of-fact fashion. To conclude, the reactions often hint towards death that is much desired for in many cases. As a staff member shares,

> 'Everyone is aware of their departure, especially in a condition like cancer; patients read their own bodies fully well. It is only about waiting for the moment to arrive. Death not only relieves the patient of their suffering, it frees the families, despite being an irreplaceable loss'. (*"sabko maalum hai jana hai, cancer main toh apne shareer ko pehchan hi jate hain mareez. Bas us kshan ka intezar hota hai. Sirf pateint ko hi mukti nahi milti, parivar bhi free ho jata hai chahe kisi ko khokar hi")*

At the office area of formal caregivers, cancer is discussed as a matter of routine life. They have witnessed it over the years, irrespective of the non-personal engagement, that cancer patients, their suffering and their deaths are discussed over tea and home-made lunches. Human beings adapt to their surroundings with time. Professionalization insists on adaptation; adapting to working shifts; adapting to consumer demands, adapting to office environment, adapting to a particular work culture and of course adapting to the demands of those above you. I am refraining from using the term compromise as adaptation can be stressful, moulding and desirable unlike a compromise. The regular specters of suffering, death, incessant bleeding and open fungating wounds, someone dying in front of you can make one use to witness it or talk about it with relatively more ease in comparison to others. Without falling for generalizations, it must be added that personality and interest also play a key role in being at ease with such sights. One of the trainees, having newly joined the team (now associated with the organization for four year), shared her experience from the first visit where the patient had a smelling fungating wound. The trainee shares that the sight was unbearable and she fainted at the house of the patient. The rest of the team members and the family held her, made her sit outside patient's room and served her water. But with time she has improved.

> "Our encounter with cancer has rounded us off, it has smoothened and polished us like river rocks." (Mukherjee 2011:338)

Why as social beings have we distanced ourselves from death, from blood, from bodily sufferings so much so that those who witness these in routine settings are questioned? I found out during the course of my fieldwork that the routine nature of the conversations on cancer (either related to the declining prognosis or death) help the team members to explain the unaware audience that it is only a disease like any other with no fully established causes and may not always be fatalistic in nature. Establishing a horrifying atmosphere using metaphors for particular diseases (Sontag, 1990), especially a disease like cancer is liable to create unnecessary havoc and often stigma. This was experienced in the field as well.

> "All this lying to and by cancer patients is a measure of how much harder it has become in advanced industrial societies to come to terms with death. As death is now an offensively meaningless event, so that disease widely considered a synonym for death is experienced as something to hide." (Sontag, 1990; pp. 8)

The team used to carry bags containing medical supplies and the bags often has the name of the organization. Sometimes, the teams commuted using the organization's vehicle with the name flashing on the doors of the car. In a few cases, the patients or their families requested the team to park the vehicle far away and not carry those bags so as to avoid stigma. In one such case, the nurse put all the required medical supplies in her bag while I adjusted the sphygmomanometer and the stethoscope in my bag. The requests, though complied to, are conspicuous attempts to avoid the disclosure of the disease. Lack of awareness is often rubbed as an easy explanation but the cultural notions of the 'type' of disease and karma were observed and shall be discussed in the chapter later.

A field visit with the team

I accompanied one of the team, for the first time, when I was asked by the organization to 'get to know my comfort level and limits in a difficult situation 'like cancer' and also to acquaint myself with the field. This was in late 2012, when I was preparing for my PhD synopsis and desperately looking for an organization rendering palliative care to cancer patients. After meeting as well as writing to different organizations in Delhi and Kerala providing support to either children or adults with cancer, hospices providing end of life support and Tibetan medicine centre known to offer assistance to cancer patients with the help of Tibetan medicine; I chose to work with CanSupport t after receiving a confirmation on the email from. At the mention of an ethnographic framework and time span required to conduct such a study, I was asked to familiarize myself with the field for a week and then write to them about my experience and my decision. I wrote a note to them by the end of the year 2012. On the basis of which, I was granted the permission to conduct my fieldwork with the organization.

Entering the field

This research work began by the end of 2012. There were fifteen teams in total with two to three teams working from one of the regional offices and comprised of the nurses who were women where as the doctors and the counselors were a mixed group of men and women. At ten in the morning, the teams would leave to the patient houses and they had to visit six, initially five, houses per day. The teams used to carry medical supplies and other knick-knacks relevant for the patient care along with the files of the patients chosen for that day's visit. The teams were provided with a car and a driver. Other than this, the organization runs a day care program conducted by the volunteers. Day care is organized every Monday and Friday of the week for the adults and the children respectively. Buses ply from AIIMS to bring outstation patients staying at the subsidized staying facility, called as *dharamshala* in Hindi, near AIIMS to the day care. The idea of the day care is to break the monotony of hospital surroundings for a day and engage in fun filled activities like singing, painting, dancing, playing, having heart to heart discussions, availing the out-patient facility and enjoying home cooked meals.

The organization asked me to undertake a few visits to acquire the sense of the field as well as share my experiences in the form of a small write up. For a week, I went with their south Delhi team. This was to experience the practice of palliative care by visiting the houses of people living with cancer, observing the physical and emotional support provided by the team members and listening to the patients and their families. We used to visit five houses a day and have our lunch by the afternoon inside the vehicle we used for travelling to patient houses. The experience was succinct yet enough to have a clear understanding of what was going to be a long research commitment. In the beginning of 2013, I undertook a foundation course on palliative care, which was attended by nurses, doctors, social workers and counselors from various institutions (public and private), jointly conducted by the organization and All India Institute of Medical Sciences (AIIMS), New Delhi. The course exposed me to the training practices for nurses and doctors as well as the counselors. The presentations and lectures included discussions on management of physical and emotional symptoms. For instance, some of the presentations included a discussion on stoma care, bed sore management, handling suicidal tendencies and managing grief as part of the bereavement counseling.

In addition, the organization conducts training courses for their staff members before recruiting them in the field. These courses are conducted separately and have respective eligibility criteria. After my PhD synopsis confirmation, I enrolled for the certificate course in counsellor training (with a social sciences background I was ineligible for training courses meant for nurses and the doctors) course conducted by the organization

(16th August to 14th October, 2013). I was introduced as a research student and was asked not to video or audio record any sessions by the tutors. Initially, they allowed me to audio record two of the classroom interactions but later some of the participants expressed their discomfort with the exercise and I was asked to stop. The course modules included interactive sessions, role-plays, field visits, sharing field work (with different home-care teams and at the organization's out-patient facility located in East Delhi) and exercises and the assessment was carried out on the basis of written examinations as well as class interactions. Five of us were provided with a certificate on the graduation day. During the course, I was suggested to travel with one of the south Delhi team as well as the north-west centre and the Bawana centre, both located in North Delhi and later choose one of the regional office for a longer fieldwork. The teams covered the area of South Delhi and the entire northern belt of Delhi including the historic old Delhi area. The locations were suggested by the organization keeping in mind my ease of access and for the reasons that these teams covered a mix of population staying at housing societies, resettlement colonies, refugee colonies, the JJ clusters (*Jhuggi Jhopadi*/ slum clusters), the villages located in the outskirts of Delhi. This was to explore and understand the nature of work the teams performed and to locate the differences and similarities in the working styles. The observed variations in the demographics of care were similar across the city so by the end of the year 2013, I had chosen to work with the two teams of the Bawana centre for reasons of their outreach to a disparate population in terms of socio-economic conditions as well as by keeping in mind the accessibility to both the rural and urban regions of Delhi. The period from December 2013 to May 2014 was exclusively spent at the Bawana centre frequenting the same households over the period of six months in order to establish a stronger rapport with the families and observe the routineness of sickness and care. A fieldwork observing prolonged intimate encounter with the dying and their families problematizes the exit from the field. A physical withdrawal was possible by citing the completion of the process of data collection but an emotional disengagement[12] required saying 'proper goodbyes' and distancing oneself gradually. Later, till August, I travelled with all the teams across Delhi NCR as well as took note of the day care activities, spent time at the out-patient facility, telephone helpline and in the adult and children day care facilities to have a detailed focus of the activities and experiences of the workers and volunteers in the organization. The interactions with the team members were conducted later so as to gradually disengage from the patients and their families at an emotional level. But it so happened that some of the families lost their loved ones in the same period and it was time to begin with thesis writing. The families tried to get in touch and were assured of later visits. After a year, the opportunity to revisit the field arose but by then the teams had stopped visiting the families as the 'patient' was no more. The challenge, therefore, was to meet the families of the deceased all over again and explore the experiences of living with loss after the bereavement visits had long been finished and the files closed. The team members often explained that there job ended as soon as the patient passed away and usually after one or two bereavement visits they stopped visiting the family. Some of the team members expressed their remorse to the fact that after developing an intimate bond, the death of the patient often disrupted the ties suddenly. In such a case, the revisit also brought in the sense of 'finality' when some of the care givers mentioned phrases like, 'now you won't

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[12] For more read Sonia Allen, Ysanne Chapman, Karen Francis & Margaret O'Connor (2008), 'Examining the methods used for a critical ethnographic enquiry', Contemporary Nurse, 29:2, 227-237

come anymore’, ‘so this ends finally’, ‘this is your home too so keep coming but it gets difficult to meet once the work is over’, ‘try to call and be in touch, he left but we are still here’ and other similar expressions.

Counseling course provided a window to compare and contrast the palliative care pursued in the classrooms and practiced in the field. The three-day-a-week classroom sessions and biweekly field visits used to be interactive and intensive. The idea was to observe in the field and share the experiences in the classroom interactions. There were two instructors who had been associated with the organization for a long period, one of them was an elderly woman, Ashley, in her late seventies, a missionary nun, who had been working with the organisation as a counsellor almost since the inception of the organization and had conducted this training course over the years. The second instructor, Jitesh, was one of the senior counselors who was trained by Ashley and used to assist her with the course now. Ten of us had joined the course and only five of us were able to graduate. Some of the participants couldn’t attend it regularly due to personal engagements and had to withdraw in the middle of the coursework or were unable to sit for the examinations. Some of them had joined the course so as to work with the organization in the capacity of a counsellor whereas others had joined it for personal reasons as they had found from earlier participants that this course had enabled people to sort their problems in personal lives.

On the very first day, in the orientation, after a brief round of instructions and a lot of encouragement the participants were asked to share their deepest feelings/memories that caused pain. The instructors shared that for those wanting to be counselors, it becomes imperative to understand and resolve one’s burdens and emotional afflictions. Counseling is an act where one had to be perceptive towards patient's unspoken problems too and many of the field observations comprised of patient and family problems and required the counselors to assist them through techniques like 'authentic listening'. We did role plays where the idea was to bring a difficult case from the field observations and resolve it using the techniques taught in the classroom. One such case required a participant to enact the role of a thirty two year unmarried mother of two in her last stage of cancer and her partner as a patient of tuberculosis and the observing participants were asked to explore her expectations from the visiting team. The idea of pain was divided into two; the pain that was caused by the self and the pain that is a consequence of struggles of everyday life. Apparently, the emphasis in the training sessions was to teach ways to address and resolve the pain caused by self in order to enable oneself to counsel others with their problems. The analogy of an already filled vessel was used. The prospective counselors were like a filled vessel burdened with their own problems and it was imperative to work on their own issues in order to 'empty the vessel' to clean all the negativity and give a fresh start. The course included training modules on handling emotions, understanding the family dynamics during the field visits, exploring the personality traits of cancer patients and working accordingly, counseling techniques for adults and children, working upon the communication skills in order to break bad news, share the diagnosis, address the sexuality and intimacy concerns, look for signs of depression, stress and burnout among the family as well as the patient. In addition, we were trained to address the psychosocial and spiritual concerns, the trauma and the skills of bereavement counseling and identifying and resolving grief. The notion of healing and forgiveness were explained as healing was essential to overcome the loss as well as to be able to let go the bitter experiences and forgive to make dying easier, akin to let go. A counselor’s work often requires breaching the privacy or exploring sensitive issues in order to be able to offer help and therefore, the instructors proposed adherence to a strict code of ethics to maintain confidentiality while rendering care.

The training, as we shall be seeing later in the descriptive account on field interactions, was only a way to prepare the counselors for the field while addressing their queries in the classroom.

Conferences and workshops on different aspects of palliative care were a part of fieldwork as such gatherings update us about the recent developments in any respective field. During the fieldwork, the teams informed me about a conference on palliative care at Fortis hospital in Gurgaon and I participated with some of the team members from the organization. The speakers shared the significance of palliative care in our society. One of the doctors and a strong supporter of palliative care cited her experience with the elderly couples in her neighborhood. She shared that unlike her childhood where elderly people had their children living with them, these days young people often settle abroad for better career opportunities whereas the parents have their own lives to pursue back here in India. Usually elderly couples are found caring for each other and it becomes difficult at some point for a spouse to manage the care work all by themselves. She shared that she was living in a colony of retired ex-servicemen and many of her neighbours had their children working as doctors in the USA whereas doctors like her were trying to care for the elderly. Similarly, in February 2015, Indian association of palliative care hosted 22nd international conference on Palliative care in Hyderabad. The conference witnessed some of the active contributors in the field of Palliative care from places like St. Christopher Hospice in UK, international organizations like Human Rights Watch and World Palliative Care Association (WPCA) active in this field, along with individual participants, institutions and organizations from all over the world for instance from Bangladesh, Melbourne, Nigeria, Belgium, Canada, USA, Singapore, Rwanda. It was a three day event (13th to 15th Feb) with speakers, presenters and participants from non-governmental organizations like Pallium India, NNPC, Organization, hospices like Shanti Avedna Sadan and medical research institutes like Tata Memorial Hospital in Mumbai, All India Institute of Medical Sciences (AIIMS), New Delhi. The conference proceedings included panel discussions, poster presentations, individual oral presentations as well as sessions on therapeutic activities like clown therapy wherein the relevance of clowns was demonstrated in order to create a stress free environment for people, especially children fighting cancer. During the entire course of events, the emerging theme was an increased focus on experiences with successful models of palliative care delivery created locally as well as internationally. In addition a plethora of associated themes like, the newly developed means of providing symptomatic care, the myth surrounding morphine and issues related to dispensing, administering and accessing morphine, the politics of pharmaceutical industry and insurance agencies, state support, spiritual, sexual and socio- economic aspects of palliative care, modes of effective counseling, bereavement and the good or bad death, notion towards approaching and accessing hospices and issues relating to incorporation of palliative care training in undergraduate medical curriculum were discussed. During one such session on death and dying, the speaker elaborated a socio-cultural understanding of death and dying and how our societies are closing themselves to this experience by putting patients in ICU's during their last hours, by not talking about death in general conversations, by never discussing death with their children and in certain religious sects by keeping children away from the funerary practices. He shared that the basic aim towards providing palliative care is to make going easy. The death should be dignified by which he was trying to emphasize on the measures to manage the symptoms at end of life. During the conference, different panels and presentations talked about care and death in biomedical terms. By which I imply, the presentations constituted of discussions on administration of drugs like morphine, wound care, nursing care, ground breaking techniques in the field of radiation oncology. I participated in the conference to widen my understanding of palliative care in India and founded it to be a biomedical initiative. I shared a section of my data as a poster highlighting the 'positives' of caregiving especially for the reasons caregiving is seen as a burden. I wanted to bring to the fore an idea where the critique of care is much more complex than understanding it as a 'burden' and the thesis is a step in this direction.

The very conference is in its 22nd year which signals the prolonged and perpetual attempts of those supporting the cause of Palliative care. While going through the literature, one often comes across statements highlighting the development of Palliative care at its nascent stage in India over all these years. While Kerala and Tamil Nadu are the two states where Palliative care has been incorporated in the state health policy, the rest of the country awaits either a state wise or a national policy on this issue. Since my fieldwork, as Dr. Ravindra Mohan (Head of Knowledge, research and Training at CanSupport) shared, a few changes with regard to the national health policy have emerged, one of which allocates 668 crore INR of annual budget (declared in 2013) exclusively for palliative care but no funds have been allotted. Similarly, the accessibility and availability of morphine has been made easy. The distribution of Palliative care services remains uneven while largely in the hands of non-governmental organizations. During the course of my work, I observed that medical colleges in states like Punjab, Jammu and Kashmir and Rajasthan seeking assistance of Organization to train their medical staff. Palliative care is a way to shoulder the burden of non-communicable diseases (NCD) like cancer, cardio-vascular problems, AIDS, multiple sclerosis, Parkinson's etc. which are either life-limiting or life threatening in nature. In India, the health care models concentrate on the control and cure of infectious diseases while the reports show an increasing burden of NCDs' as well as disabilities' and the old age related care to improve the quality of life. Dr. Ambika Rajvanshi, the CEO of the organisation, in her interview shares an estimate that, by 2050, India shall be facing a lot of challenges in terms of providing care to a growing number of populations suffering from NCDs' but there are no concrete provisions of supportive care.

Consolidation and expansion: Structural changes in the organization

The NGO had undergone drastic transitions a few years before I began my fieldwork. In the last phase of my fieldwork, I audio recorded a few short interviews. In one such interview the director of the home-based care programme, Dr. Reena Sharma, who was recently appointed to this position, spoke about the road map for the future,

> 'Recently, we have been expanding a lot. We have a lot of new and old people. Our first thing is to make the older one's match the newer one's. That's the main challenge. No one has done palliative care *earlier* (emphasis mine), so the people

> who join new they have less exposure to it. So the focus is to bring them at the same pedestal as the older once and it will take close to two years.'

Similarly, Dr. Rajvanshi opined that for any organization to perpetuate and sustain over a period there has to be a time for consolidation and a time for expansion, consolidation is basically the way to a planned expansion with teams and even with the funding agencies. Though the two interviews were conducted separately, somewhere the internal disruptions were handled by focusing on this aspect. This was done through conducting workshops on gender sensitization, stress management, role of communication and good counseling, addressing grievances by the support staff. These workshops were conducted by the experts in the field from around the world.

While the organisation remains a model organization in North India, the ideas to replicate something similar in other parts of the country also came up from within the organization as well as the visitors who came there for training. Dr. Rajvanshi in her interview shared that the organization intended to span out of Delhi indirectly by sharing their expertise with other states. I witnessed it in the case of doctors and nurses from public hospitals in Punjab. Many of the team memebrs, also went to Jammu and Kashmir for conducting a training course in palliative care. She was of the opinion that this kind of model was more acceptable in the northern part of the country as palliative care culture in South India was different with hospitals playing active role in providing such services. This reminds me of Baviskar (2000) who moots down the replicability of a successful model by linking it to the scale of implementation.

Since, the organization had two support/teams FST (field support teams) teams, east and west, supervising and supporting the work of the rest of the teams. These FST members were endowed with powers to critically supervise the work of the team they used to visit. In some teams, the strained equations amidst the team members disturbed the team dynamics. The FSTs' and the households seeking palliative care services barely missed such differences and prejudices and these were directly (through telephone help-line services) or indirectly (when the head office observed discord through unspoken acts like lack of co-ordination while maintaining the patient files) brought to the attention of the higher authorities and resolved through mutual yet confidential communication. As Dr. Rajvanshi shared,

> "Cancer is a journey. When we began, we began with the home care, as usually people were diagnosed in their late stage, mostly fourth stage. In last eighteen years, awareness has increased much more, hence, we started working on different programs as different programmes address different issues, like telephone helpline which begins even before diagnosis for instance to answer questions related to medical tests to diagnose cancer. Peer support group program which is meant for newly diagnosed patients for instance, (Dr. Rajvanshi animatedly enacts the whole communication between the newly diagnosed woman patient and a survivor) If I have breast cancer and I am made to meet a survivor they are in a better position to handle issues like how to wear a *saree*. I share my pics (sic) during the treatment, share the information that right now I am wearing prosthetics, a padded bra. The new patient answers, oh! I never knew.

> People will call me *ganji* (a hindi term for a bald woman). The other one says pull my hair even I was bald, she literally pulls it, the entire enquiry becomes so personal. You relate to the person so very closely, that's what peer support is all about. Because you need it in the beginning as later the needs change. Out-patient care when you are undergoing therapies there are a lot of side affects which even the oncologist doesn't address, for instance chemotherapy makes you feel nauseated or radiation leads to skin rashes, so doctor and nurses in Palliative care handle it. Day care is for kids, rest and respite. Destitute families where bread winner won't earn. Bereavement support in all cases as well as planning a programme to support families undergoing 'delayed grief or prolonged grief'."

Thus, the organization is providing free-of-cost support by maintaining a care continuum where the supportive care begins from the telephonic helpline addressing multiple queries, while maintaining confidentiality, beginning from the questions regarding cost of medical tests, information on cancer screening, then enabling peer support groups in case of a positive diagnosis, taking referrals for home care services, while simultaneously providing the out-patient facility to patients coming from outside Delhi for hospital visits. The telephone helpline, in particular, provides information about their services as well as information regarding cancer-related facilities in and around Delhi. They also maintain a directory for referrals to blood banks, hospitals and doctors, financial aid, travel concessions, prostheses, etc. The helpline assistants listen to and offer confidential emotional support to people struggling with cancer as well as their caregivers. The telephone helpline staff also provides referrals to all the teams. Those who need home care are registered for this free service when they call. Those who wish to attend the monthly Peer Support Group meeting are also provided relevant details. Beginning from half past nine in the morning the service goes on till half past five. I was able to spend three days with the helpline staff which included a training workshop on communication focusing on distress calls from the clients. During my first day at the helpline, I met this lady with a certain sense of calm and empathy in her voice, probably the key traits for which she suited the profile. She was extremely sagacious and her conversations over the telephone made me realize the nuanced expertise with which some people handle the most difficult conversations. Over the years, she has provided emotional support to many callers looking to unburden themselves. She finds this helpful too as she adds, " many life shattering questions arise in front of you…mentally disturbing. Sometimes it makes you feel unresponsive but working in this field renders you maturity. I have been able to envisage my life from close quarters…..my relationships as well. After listening to them, my life appears so easy." Those working at the helpline shared that they established long lasting bonds with many of the callers without seeing each other ever. They shared that the callers often felt that home care programme is important not for anything else but the time or bonding it provides to people in their last days. The home-based care programme is the oldest and the largest programme of the organization. In addition, the organization has a day care programme completely managed by the volunteers. The idea behind day care is to provide comfort and relaxation to the patients while listening to their worries, their stories and sharing with them stories of motivation. The day care is a bi-weekly programme with one day for young patients which include children of all ages and the other day for the adults. The day care provides an out-patient facility to the patients too where they are checked for any discomforting symptoms and providing medicines. My experience with day care showed me the fun side of care where we could sing and dance together, play games, colour drawings, engage in art and craft. The volunteers brought fresh home-cooked food in the day care and often provided them with protein health drinks like horlicks.

The organization provides bereavement counseling in the case of death and supports the bereaving families by organizing events like 'Remembrance Day' and conducting multiple visits if the requirement arises. In addition, the organization has offered employment to some of the informal caregivers who came in touch with them while caring for someone in their families. They were trained and recruited in the organization. The rehabilitation program for patients and their families tries to generate modes of self-sustenance for poor families in case the breadwinner is unable to work anymore. This includes buying a cart and providing supplies for the first time. The supplies may include vegetables, fruits, groundnut and popcorns, eggs etc. The idea is to generate a means of income where someone from the family can sit and sell the supplies. In many cases, people are provided with sewing machines so that they can generate some income by tailoring clothes. In case of children, I found out that when a seven year old Tamanna wished for a bicycle, she was gifted one on her birthday.

Chasing referrals and spreading the word

In addition, the organization had two community nursing officers who used to spread the word by visiting a particular location in Delhi, covering it on foot despite the weather conditions for a door to door access, distribute pamphlets (with information about the telephone helpline as well as information on early symptoms of the disease), they used to conduct small talks of spreading awareness among the locals too. For instance, to raise awareness for breast cancer and cervical cancer, they located a local *anganbadi* worker and asked her to call the women from the neighbourhood to listen to a small talk on self-examination for breast care and looking for early symptoms of cancer. Another task during these visits was to get referrals, we distributed pamphlets at chemist shops, other key shops in the locality, the dispensaries and the primary health centre and shared that the organization offered free-of-cost care services. The two CNOs' used to divide the responsibility, with one visiting the field as mentioned above while the other visiting the institutions to get patient referrals. I went to three institutions in Delhi, namely Safdarjung Hospital (where we tried to trace the nurse known to the CNO who provided us access to the OPD where we would distribute the pamphlets by locating patients in the corridors of oncology department or cancer patients waiting outside the room of the doctors but never entering the doctor's room), the radiation department of one of the very reputed public medical college[13] in Delhi where we met the patients in the OPD of only one doctor[14]and to Institute Rotary Cancer Hospital at AIIMS where we were inside the

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[13] The identity of this institute has been kept confidential for the reason that there was an individual involvement on the part of only one professor which makes it easy to locate his identity unlike the other two sites where the institutions were involved.

[14] A professor of radiation oncology and a vocal supporter of palliative care services, he referred his patients sharing with them basic information about the organization and asking them to meet the CNO waiting outside. He shared his notion of making all sort of relief available to the distressed patients and families. He shared that despite being a practitioner of allopathy, he used to prescribe his patients with cervical cancer to use Tibetan medicine which could be brought from the alternate medicine clinic in Nizammudin associated to Men Tsee Khang (Tibetan medical and astro-institute Dharamshala, Himachal Pradesh). According to him, he had observed and kept a record of improvement in quality of life for these patients over a period of

OPD and interacted with the patients sitting outside a small room where doctors called them one by one and later went inside the room where the close to five to six senior residents, adjusting themselves around one small table, interacted with the patients and prescribed them pain medications. There was a cramped space adjoining this room where the volunteers from other organizations waited for referrals along with us while the junior residents carrying out their research projects with the patients asked them questions from a close ended questionnaire concerning their fear of the disease, belief in God, diet supplements etc. Often, so happened that the doctors would ask the patients based in Delhi and NCR if the team was visiting them and would send them inside to talk to the CNO.

Palliative care and the interest of private players

During the course of my fieldwork, two prominent changes I could observe were the display of hoardings by some private players, cancer specialty hospitals, in Delhi and two leading private hospitals promising to provide palliative care post-treatment. The team reached at a patient's house who had been frantically calling since early in the morning as the urinary catheter of the patient had come out and needed to be inserted again. The patient had been receiving treatment from one of these leading private hospitals. When we reached, two people came out of the house while the family welcomed us inside. The catheter has already been changed as the hospital had very recently come up with palliative care facilities. Though not free, as the visits incurred some monthly charges, the family found it simplistic. Palliative care is promoted as a 'high touch and low tech care'

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five years but he couldn't publish his findings in any journal of repute for the reasons associated with the politics of hegemony and legitimacy to of a particular brand of knowledge.

and an economically viable option. However, the above incident very subtly hints towards the ‘infiltrating profit making approach’ permeating the very field as well. The family shared its sense of contentment that they had the benefits of free as well as paid care, both from the organization and the hospital in discussion.

This recent development was interesting given many paradoxes observed in the field. On one hand, the private hospitals realise their need to widen the ambit of care and subsequent profits whereas on the other hand one finds pictures displayed from the annual events in the organization’s office including state dignitaries like erstwhile chief minister of Delhi and former Prime Minister’s wife cutting ribbons and lighting lamps over the years but neither in Delhi government hospitals nor as a national policy have we seen any benchmark developments. This makes one believe that either the relevance of palliative care in assisting the debilitating and dying is misplaced and not immensely effective or as McDermott et al (2008) refers it as a lack of political will. In the subsequent chapters, the idea is to explore and understand the interventions palliative care supporters claim to make through an ethnographic exercise while swinging between the fluid lives of people who are living or have lived with cancer.

> Palliative care, as suggested by its advocates, is an action to settle the chaos and uncertainty synonymous to cancer (Sontag, 1990).

Who are the advocates of palliative care? Are they the organizations working towards it or the health care practitioners and agencies working on ethics of care or those opposing the practice of euthanasia? This can be an exhaustive exercise. An anthropological inquiry like this may not provide answer to this question but attempts to provide a picture of what constitutes palliative care and how does it impact peoples’ lives and the answer to these two questions are approached by observing the lives of people who are directly involved in delivering and receiving this care. How they perceive palliative care and what constitutes their understanding of life, death, disease, suffering and most importantly care? The meaning making processes in the individual lives may not be the best mirror to generalise for a larger cohort but are honest glimpses of local individual realities. Palliative care, therefore, owes its existence to the multiple agencies involved in care from funding agencies to the hospitals, which are the sites for accessing the target populations, along with the team members and most importantly the households affected by cancer.

Formal caregivers understanding of cancer through care interactions

> "*why palliative care management is no idealism nor the opposite.*"
>
> Sandman (Kellehear 2007a: 374)

In one of the initial field visits, as a part of training for the ongoing counseling course, one of the participants Shaily and I were asked to visit the out-patient clinic located in East Delhi. It is half-past nine in the morning, when everyone is settling down in the clinic, greeting each other with wide smiles and hugs and welcoming us enthusiastically as the patients begin to pour in. The early two visitors are children aged four and twelve. The younger one's father works as a nurse in the cancer facility of the state hospital and is aware of the brain tumour, the child is dressed in superman t-shirt and matching blue pants with goggles. Everyone hugs the kid, the nurse whispers in my ear, 'he does not have much time' and goes towards Rahul, the twelve year old, and his parents who are a little hesitant to enter the facility. They are directed to the doctor's room while the boy sits next to me and is given a color book and crayons. I begin to talk to him about his hobbies and Shaily joins me. After sometime, the parents come out of the room and see their son, the mother rushes to another room. I sense a little discomfort and follow her as the nurse and the counsellor are busy with the four year old. Shaily follows me too. I hold the mother's hand and the nursing assistant, who saw us entering, gets her a glass of water and makes her sit on the chair. While she is crying, Shailly tries to comfort her by keeping patting her shoulder, looking visibly shaken herself. Nursing assistant comes forward and initiates a talk and looks at me directing her eyes to the adjacent room. I sense that she wants me to call the counsellor and I rush for her, desperate to help the crying woman expecting the doctor must have shared something really sad. The counsellor comes in while the nurse bid bye to the four year old and his parents. She sits with her while I stand on a corner, in the meantime the nurse brings Rahul's father inside. The counsellor looks at them, father asks, 'will be survive' *("bach jayega na").* The counsellor looks into their eyes, holds their hands in hers and very softly says, 'hug him, you need to love him till he is with you' *("gale lagana hai or bohot pyar karna hai jab tak apke paas hai").* Listening to her, both of them started wailing loudly. The nurse hints me to sit outside with the son and the counsellor suggests them control so that their son is unable to find out as he will lose his courage (*"himmat toot jayegi uski"*). As the family left the clinic, Shaily reduced to tears; having lost her thirty year old brother after a sixteen yearlong battle to osteosarcoma she was reminded of his younger days when she saw Rahul and his family. This was discussed in the next training class and was answered as a result when 'pain connects with pain' and the trainees were asked to shun their pain

so as to embrace the responsibilities of a counsellor, ‘a healer’. Many of the counselors and nurses shared their initial experience in the field as displeasing sight of living conditions, of the festering wounds and obnoxious smell emanating from them, fainting while visiting people in such conditions. Many nurses explained that their training made them get accustomed to the sights of intimate body organs, oozing fluids as they were required to do care work but the their routine jobs in hospitals and private clinics were never similar to the field where cancer patients had something ‘different’, firstly for the reason that the organization only worked for cancer patients and they came to witness.
The team members especially the counselors and the nurses came from similar social fabric, witnessing similar needs in their own households, and experiencing similar suffering in their personal sphere. Once a nurse, while returning from the field, confided that sometimes she takes every little symptom to be a form of cancer, even if it is a blister in the mouth. During the training course for counseling, many of the participants shared a similar concern from the field which was answered as a ‘matter of precaution’. On my next interaction with the nurse, she shared that if she is ever diagnosed with such a dreadful disease she would not pursue treatment no matter what the stage is. She further stated that being a nurse she has been close to the patients undergoing chemotherapy as well as radiation therapy and in most cases since cancer keeps coming back, the end days are traumatic.

Similarly, one of the nurses added her discomfort with the ruthless (“*nirdayi”,* cruel in English) manner biopsies are conducted these days in public hospitals (she cringed while tightening her jaw, closing her eyes and constantly shaking her head with hands on her ears) where she narrated patient’s experiences of technicians “throwing equipment on their feet while performing the procedure and leaving the instruments hanging on the incision”. After the patient visits, I used to return to the regional offices’ and converse with the teams who would be busy reporting to the head office with the patient names and filling their files with the field details. One day a counsellor shared that life in the field of palliative care had made him sad. Listening to her another counsellor from the second team added,

> ‘What are we doing to ourselves? Only burdening ourselves with the pain and suffering of the patient. Our personal lives are distressed as well. Detachment is not always possible.’(“*hum apne saath kya kar rahe hai? Bas khud ko auro ki takleef ke neeche dabate rehte hai. Humari khudki zindagi main pareshani hai, sab alag alag rakhna humesha* possible *nahi hai.*”)

Rest of the team members hailed her ‘dialogue’ and began to address as the tragedy queen of Bollywood ‘Meena Kumari’ (a yesteryear actress known for her tragic roles).

The instructors discussed the drawback of attachment in the field of palliative care and referred to it as ‘compassion fatigue’ and the future counselors were encouraged to develop hobbies like gardening, quilling, painting, etc. They were introduced to creative ways of caregiving like music and art therapy, creative visualization etc. In the entire duration of two months, a pattern emerged from the classes where the pedagogy focused on counselors staying in touch with their own feelings. Apparently, a graduate degree was the minimum essential criteria of qualification but the decisive factor used to the interview process where the participants were tested for their sensitivity, perceptiveness, any previous experience of cancer related death or dying in personal lives etc. The training sessions had a strong focus on the notions of religiosity and spirituality and often there were heated discussions over euthanasia and atheism.

Later in the field, team members were observed to not exactly follow any rule books but pursue the matters more flexibly while sticking to the local moral values. The balance between being ethical and moral was based on the inter-subjectivities played out in the field and if understood in this light, care practices were complex to be understood through a moral prism of good and bad and were instead contingent upon the locally suited. I shall be discussing this elaborately in the chapter on care. For instance, in one such session, the discussion was oriented in a way such that believers was referred to as a given category and how counselors needed to resolve any hostility, emerging after the diagnosis or dependency issues, towards the god. I asked what if the patient was a non-believer, an agnostic or an atheist, keeping in mind the arbitrariness of the boundaries that distinguish these categories from those of the believers. I was strictly told that no such categories exist and in case the counselors find such people, they should be considered as cases unworthy of counseling as they come from dysfunctional families. The assumption sounded overreaching and I discussed it with participants on a one-to-one basis after the class. Three of them attributed it to the instructor’s personal background as a devout missionary nun while two explained to me that the idea of not believing in a god was a pure hogwash. In the field, some of the counselors, from earlier training sessions, expressed their displeasure with positing questions to the patient in such a way that God was always a given category. For instance, one of the counselors during a field visit asked me if it was right to ask people whether they believed in god or not and if they were angry with god due to their illness or were in a conflict with god for their current state of dependency and suffering. She shared that the job of a counsellor was to provide the patients with a platform where they could open up about their emotional, social and spiritual issues by themselves instead of ‘infusing their minds with the idea of god’. She further added that ‘she felt the organization would never be able to provide a good training to the counselors’.

Later, in the field, many of the counselors were observed to either go by the rulebook remembering the training sessions or follow their own understanding and there was a divided understanding emerging from the way palliative care was talked in the training sessions and the way it was practiced in the field. It was not as if those who liked to defy the coursework[15] training pursued counseling care as per their whims and fancies instead they were open to reading more in the field of cancer care and often provided me with the links to the websites or the books they read related to the patient issues. While I was pursuing the course, during one of my field days, the counsellor from the team suggested his discomfort with the ‘utopic’ idea of care leaving no scope for improvement or improvisations. He shared his discontent with the way the topic of euthanasia was discussed during the training session and expressed his feeling that people were not ready to discuss the idea of euthanasia as it was understood as ‘killing’ and encouraged me to discuss it. I did so on his suggestion in the next class and the understanding of euthanasia emerged as an act of interfering with the natural course of life. I shall be discussing more regarding this issue but for now we must understand that the incident reflects that not all the participants adhered to a particular set of values promoted in the course work and the

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[15] They found the course structure a little outdated stating that the earlier batches shared similar notes and course material, based on one book. A few counselors identified themselves as atheists and expected spiritual counselling as pure hogwash. While in the field, they listened to so many of the patient spiritual issues and therefore, the discontent on the part of a handful of professionals was a personal matter.

individuals were open to be flexible in their approach, keeping in mind the patient and family needs. The organization had a more democratic style of functioning and it was up to the formal caregiver to approach the case through a chosen perspective be it religious, spiritual, psychological, sociological or a combination of all of them etc.

In a similar way, during the training there were discussions on the legal issues involving families and patients and the stance of the organization. The organization was not providing legal advice but the counselors were asked to suggest for legal aide to the patients after discussing the issues among the team and the organization too. While some of the team members were hesitant to take up any such issue on their own, others often sought of discussing it with other teams and the organization. In one such case, the senior counsellor, who was accompanying the fresh recruit, suggested a patient to write a will for his wife. In later visits, his wife shared that raising this issue led to a cold confrontation between the couple and their sons and their respective families. The couple was angry with the counsellor and the team suggesting that their children would have never neglected their needs had they not raised this issue. The team had suggested the counsellor to avoid such suggestions and the newly recruited counsellor told me that the despite his training he was apprehensive about the discussion on legal issues. The team listened to them for more than an hour and expressed their regret over this situation but maintained their stance telling them that it was a well-intended suggestion. On the next visit, the couple asked the team not to visit them anymore. After a month, the team received a call from the wife. The patient had expressed his desire to meet the team and wanted to thank them stating that his will assured his wife’s financial independence after his death as their sons had turned hostile after coming to know about his will. A few days later, the patient passed away while the team and his wife made sure he was well taken care of in his last days. The entire course of incidents happened over two months. The interpretations changed over the entire period of observations which reflects the perils and promises of an ethnographic exercise on the one hand and throws light on the way meanings are acquired in the inter-personal relationships given that an account of a single visit wouldn’t have been a holistic summary of the series of events, understandings and interpretations.

Also, the counselors, as well as nurses and the doctors, were supposed to keep a record of their observations. There were different psychological scales to measure the emotions and the fresh recruits often had trouble figuring out if the anger was to be put on a scale of 4 or 6 or even the pain ladder. But the team members often explained to them that these scales were only to acquire an idea about the severity of the problem and probe accordingly, be it through counseling or using medications. Many of the counselors and nurses expressed their abhorrence to the exercise of marking scales and filling up other technical details but their significance was understood in later visits when the absent team members were replaced by another personnel who would look at the patient history while communicating with the patients and their families.

As the patients and the families understand palliative care

In the case of households’ witnesses to the presence of invading cancer, palliative care as a term in ‘English’ was not understood clearly. By which it implies, that the meaning of ‘palliative’ was unclear and was not even mentioned in many cases, as I witnessed during the visits. The introduction was provided as a, ‘free service for caring the cancer patients from an organization which runs on charity’.

Many families and individuals, usually poor, living in slums and in certain cases on roadsides, were often seen asking for financial help and were denied as the organization could not provide any money. The team members explained them that their task was to do *dekh-bhaal*(to take care) and provide for ration and rehabilitation under certain conditions. During the conversations, people gave different explanations for what they understood by the team's work. Some of the narratives are,

> 'They come and provide us with medicines *("dava-daru")*, and teach us how to care *("khayal")*.
>
> 'It is a kind of selfless-service ("*seva*").
>
> 'They come to see us, if we are fine or not, spend some time with us' ("*aate hai dekhne ki hum theek hai ya nahi, time bitate hai humare saath*")
>
> 'They are doctors, come and do our dressing as well as physical check ups'
>
> 'They are more than a family to us; while everyone left their support was constant' ("*Parivaar se badhkar hai, sab ne chod diya par inka saath bana raha")*

These are some of the narratives shared. Most of such narratives were shared without any emotionally laden undertones but I also feel that these experiences must only be used to perceive a surface understanding. The tacit understanding stands a chance of being laden with expectations or the very fact that the people receiving care were sharing their experiences with those who were providing them the care. I as a researcher accompanied the team and I was often understood as one of the team members. Despite clearing the ground about my position in the team, I very much stand a chance of being closer to the teams.

Founded and unfounded fears

Observation based experience has long been supported in human society not only for knowledge development but to learn various tricks for survival in this world. During the field visits, many of the nurses shared their fears based on observing their patients over long periods (in many cases years). This is to see how repeated observation frames one's understanding of a disease despite being medically equipped with knowledge to counter the experiences from everyday life.

Biopsy is a basic test wherein the tissues are extracted from the site of tumour in order to test for its malignancy. I found it not from one or two but as many as six nurses that biopsy was often seen as a culprit. Though required for a confirmed diagnosis, biopsy, as per the nurses, aggravates the tumours. The common lament was that the tumours proliferate faster and grow huge in size in comparison to the small node that existed earlier. In case of an oral cancer the mouth which was opening enough to take regular feed gets shut and begins to smell. 'If ever asked to undergo biopsy, it will be a no.'

Anu, a Bangla woman in her late thirties, who used to work as a domestic help in '*kothis*' (big houses belonging to rich people) was diagnosed with cervical cancer two years ago, since then her life has been 'hanging on the cliff' ['*aise lagta hai jaise kabhi bhi mar jayenge* (it feels like (i) can die anytime, *latakrakhi hai zindagi* (life is hanging (precariously)"]. It has been more than a year since the team has been visiting her; she shares a very special bond ('like a sister to me') with the nurse who is a woman unlike the doctor and the counsellor which makes it easier to share her intimate concerns now that her husband is soon returning from jail after eight years of imprisonment. In this visit she was found lying low, not eating anything since last night, neither consuming her regular dosage of morphine due to which she is a lot of pain cringing on the bed. As we enter the room, she lifts her eyes while her son explains her condition to us. The nurse sits by her side and asks the reason she has quit eating and consuming medicines. In a faint voice, she shares that this time the biopsy was performed rather callously. They inserted the needle four times to extract the tissue, at that moment she only felt something probing her insides but it began to hurt after she reached home. The man who performed the biopsy told her that he could not get the right amount of sample during initial insertions and it is important to repeat the procedure. The team explained to her the importance of getting the right sample to see if her jaundice is not because of a metastasised condition. To which she said,

> *'samjhati hu main, par jaanwar ki tsarah sui dalte hai, aram se bhi toh kar sakte hain, dard hota hai'* (I understand it, but you do not insert needle as if I am an animal, they can do it comfortably too. I feel pain) (winces in pain while getting up to drink some mango juice at the behest of the nurse)

Similarly, on meeting Shanti aunty who is in her late seventies, stays with her retired husband, has her right breast removed eight years ago and has been declared cancer free now, shared her experience with biopsy with me during one of team visits and said, 'no one in government hospitals (*sarkari haspatal*) cares how they perform a test, why to blame them when they have so much of rush to handle (*unhe bhi kaise bura bolien jab log bhi itne aate hai wahan*), in my case they made a small incision and extracted the tissues but they dropped their instrument twice on my feet, I screamed out of fear. This was young boy who left something hanging to the opening of the incision while picking up the needle…I was scared that the weight of this clip might tear the skin more, thus widening the incision, then he inserted another clip inside and twisted it to take something out. I could feel it. He repeated the procedure three times and with each twist I felt even if there may not be any cancer it will come up with so much of tearing around (laughs). But this boy was very ruthless, his body language extremely callous and may be a little shy on seeing a breast…he appeared a novice to me as he was being guided by another man. He kept on fidgeting with those instruments poked inside my breast while I was witnessing the entire session. I was terrified and my body was cold. I could feel both of us, him and me, wanted the entire process to get over at the earliest! When I returned home, the pain could be felt. I had been asked not to perform any rigorous task with this hand like lifting weights. But, with so much of pain I wouldn't have been able to do anything even without such instructions.' The team told her that he followed the correct procedure and despite all skepticism today she is fine and disease free because of the same procedure but on our way back to the office, the nurse whispers asking me, 'You don't you feel the elaboration by Shanti aunty was too gruesome? I personally shall never undergo a biopsy…no matter what! (Looks up towards the car ceiling mumbling "god...god" Shaking her head and mumbles again "tsk tsk tsk..so scary".)

Another nurse who has been working with organization and has tended to many patients with osteosarcoma (bone-cancer), confided how she fears every time her children fall down while playing. She shared that over a period of six years she had been with many patients with osteosarcoma who developed it after injuries caused from fall or getting hit by something at the same place multiple times. I was informed that there is a lot of uncertainty over this issue whether it is the injury that causes the tumour or the tumour formation weakens the bone causing an injury thereby making it a chicken and egg situation. Nevertheless, the nurse met with an accident hurting her pelvic bone a few days before confiding in me. Every time both of us visited a patient with osteosarcoma and during our conversations we made sure to ask how the tumour began the patients would say something like ; ‘Seemakshi whose leg was amputated due to osteo-sarcoma : ‘I always had pain in this leg since I was nine or ten, my mother told me I had fallen and hit myself once… never knew it would develop after so many years!’, Rohit a young boy in one of the rooms of the out-patient clinic of the organization shared, ‘I was hit by a ball on my toe, then next time I was hurt at the same point while I was trying to hit the ball to score goal and later I began to have pain and now this...’

One needs to consider the human reliance on experience and witnessing despite being trained in a body of knowledge. The nurses are educated professionals and aware of the significance of biopsy and its procedural requirements. The patient experience is contingent upon their anxieties, frustration with waiting for long hours before it is performed and callous attitude of the staff in public hospital. But the test is the only way to assure the presence of ‘malignancy’. In such a case, the attitude of care deliverers allows us to look into their world views which are not based on their professional trainings but on their association with the self which easily associates to the perceptions and experiences of their patients pain and discomfort caused due surgical procedures.

The interactions form a crucial part of the everyday life of the people with cancer as well as their families; it establishes trust, a key value that promotes good care. The process of establishing and nurturing social relationships between the Team members and patients and their families promotes good care. The inter-personal bonding was found to be therapeutic in the field. As Verkerk (2011:151) shares while commenting on the ethics of care,

> ‘Good caring involves a view on the caring relationship as an ongoing process. That is, care requires specific moral qualities and the four ethical elements of attentiveness, responsibility, competence and responsiveness are related to the four phases of care as a process.’

The redefined spaces of existence and functioning, the equipment’ assisting for a ‘normal’ body functioning and the sense of self before and after are the categories helping in meaning making, unknowingly though. These categories subtly offer a paradox to be lived in. The narratives of diagnosis, getting treatment, improving further are entwined with narratives of lives changed forever, of loss (visible and invisible), of uncertainty are complex and difficult to articulate with so much of a sense of fluctuation. The team members usually acknowledged these in-flux realities which probably was the reason for continuing with the visits despite being perfectly disease-free, in the medical sense of the term.

> “For clinical experience to become possible as a form of knowledge, a re-organization of the hospital field, a new definition of the status of the patient in the society, and the establishment of a certain relationship between public assistance and medical experience, between help and knowledge, became necessary; the patient has to be enveloped in a collective, homogenous space.” (Foucault. 1976:196)

This section very specifically focuses on doctor based experiences as patients and the other team members (both the counselors and the nurses) often shared their interactions with the doctors and brought to light the domination or hierarchy experienced on a regular basis. During the interactions with other team members, a subtle ease could be felt when the families and patients had to interact with the counselors and nurses, more so among the households belonging to middle and lower socio-economic backgrounds, education also played a key role. While elite families were often seen discussing the issues with doctors, the communication used to be in English and not all the team members were necessarily well versed with the language. During my visits along with the team, in the absence of doctor, the communication would be distant. Once it so happened that the entire family began to converse in English while I was with the nurse and the counsellor and I became the spokesperson for the nurse and the counsellor. The team later laughed saying even their doctor would not have been able to communicate 'so convincingly'. I, on the other hand, felt absolutely awkward. The family was fully aware of my educational background and my role in the team. While very few doctors were appreciated for their approach, some of them were darling of the masses. The nurses, the counselors and the patients often spoke extremely positively of this doctor. Otherwise, irrespective of gender, one used to often hear stories against their conduct. The organization conducts monthly meetings where all the teams met and shared their dilemmas and requirements for medical supplies. I used to participate in these meetings and many of counselors and nurses used to ask over lunch, if I observed that a few doctors held the stage and did not allow them to speak and share? However, I did observe that nurses were the quietest group.

A normal day of work was similar yet so different with each household. The similarities could be seen in acts of monitoring blood pressure, wound dressing (wherever applicable), checking the medicine box to understand compliance not only for morphine but for other medicines especially for constipation, ulcers in the mouth, nausea, pain symptoms, for sleep, for hunger and other related issues. But the range of differences emerges in the interactions with different households. This is contingent upon the period of interaction, ties with the caregiver, perceptions regarding patient, individual ties of the patient/family with the doctor, the nurse and the counsellor as well as their respective gender especially in the case of counselors.

The notions of professionalism within healthcare takes into account a certain level of disconnect. The team members, within clinical settings as well as field oriented settings, are made to attend trainings to combat ‘compassion fatigue’ and ‘burnout’. ‘Detachment’ is emphasised for a better care. The meaning of detachment as interpreted by individual professionals can vary and was not much talked about during the very many workshops organized for training the team members. In the case of the very organization, nurses and counselors are much grounded in their approach despite facing distress in some situations. Doctors on the other hand, with an exception of one or two, were largely ‘distant’ in their approach when they initially joined the organization. As shares the doctors from the organization that initially she ‘found it difficult to come to terms with dying patients and would be upset every time a patient passed away. Another colleague, a doctor herself, helped her understand the atmosphere and learn detachment’. She shares,

> “It took me a year to overcome my earlier beliefs. As a doctor, I had been trained to cure the patients, at least try to treat them in ‘the best possible way’ and now,

> suddenly, I was expected to work upon dying people, where no cure or treatment was ever going to help. This would upset me every time a patient passed away but the new kind of work also showed me how I was trying to bring comfort to someone who was nearing death; it was about care and not cures. Most of the oncologists, I know so many among my friends and family, are arrogant….like…like see them as God. (They are) Not ready to accept palliative care…as somewhere it defeats their 'control'."

Some of the counselors and nurses scorn this kind of behaviour but are non-complaining for one basic reason that they have a stronger connect with the households given that each centre has only one doctor while there are two or three teams per centre which curtails regular visits of doctors with the team mates. Unlike the clinical settings, more autonomy lies in the hands of nurses and counselors. In the field, I could spend relatively longer time with the nurses and the counselors in comparison to the doctors, given the fact that doctors are less in number in comparison to the nurses and counselors. One of the office staff reasoned it to the fact that the organization runs on charity and hiring many doctors implies much more amount of remuneration.

During my association with the organization, I have visited the field with eight doctors. They came from different backgrounds of army, NGOs and private hospital set ups. One of the doctors with his earlier experiences in rural areas as well as working among marginal groups of AIDS patients on the contrary found it easier to communicate. His ability to accept the realities of dying made it easier for him to communicate among the patients along with his language skills where people speaking in Haryanvi or UP dialects of Hindi could be easily understood. Another doctor who came from an army background was subtle in his demeanour and during the visits his humble communication made people lap up to him and ignore the nurse and the counsellor as well. The intimacy of the nurses and counselors is found far stronger but in his case patients were more expressive of their concerns. The other team members in his team didn't speak much in front of him about his interactions but lauded him in his absence. The nurses shared,

> 'Have you ever seen him getting angry or scolding us? In other teams doctors are known to be strict with the other members but he is humble and interested in his work. Every morning he asks all the details about the patients, he can read the files too but he makes an effort to talk to us and obtain first hand information. In some of the other teams, the nurses need to update the doctor. Here, he will ask you even before you are going to update him.'
>
> 'He asks for our opinion all the time', a counsellor added.

During my visits with the doctors, I personally never observed any kind of open display of hierarchy, dominance. However, in the subsequent visits with the rest of team members, and not only the team members but the patients used to mention problematic conduct. For instance, a lady who has survived cancer for last four years and had mastectomy of the left breast, shared her hesitation with a male doctor. 'I am of his own age and we hail from villages. He must keep his hands off my back but he never realizes this.' The nurse and the counsellor had mentioned her apprehensions and discomfort to the doctor but (according to them) he never paid heed and instead was always eager to visit the patient at odd hours. The patient shared with me, 'I have asked them to come without the doctor. I do not have problem with all the men'. In another case, a patient's family shared the way in which doctor used to communicate with the nurse. ‘She/he does not scold the nurse in your presence but otherwise he is rude to her.’ Another patient shared an incident during which the doctor ‘mocked the nurse’s qualification’. Similarly, a patient shared about ‘change in body language’, ‘disparaging the nurse over her looks or her style of work’, the counsellor from the team later confirmed to the allegations stating that the doctor is a ‘little sexist and patriarchal’ in her approach. The counsellor, during a visit, when the nurse was not with us shared the very observations with the doctor asking him politely ‘to change his way of communication’. The doctor looked at me as if seeking affirmation for the observations and I admitted that the remarks were often ‘distasteful’. The doctor later admitted that the different ‘cultural background, sensibilities and voice tone’ are the basis of ‘our’ misinterpretation. After leaving the field (August, 2014), in the summers of 2015, the nurse shared that the doctor’s behaviour has drastically improved and she is very happy to work with him. I never mentioned our interaction with the doctor to her.

Another nurse once shared how Ravindaran, a retired peon, a patient of multiple myeloma, was reduced to tears, during his interaction with the doctor. On our next meeting, I accompanied the team and in the absence of the doctor we asked him about his experience with the last visit. He desired to know what exactly my work is about and the nurse interrupted, ‘she is a nice girl and will not disclose it to anyone, you can share whatever you want to’. In the meantime, his wife bought us a homemade snack; I explained to him that I am trying to look at various facets of care provided to him as well as the way he looks after himself. He shared, ‘It was their second visit to our home. I did not know much about my disease and no one at the hospital has been very clear about its prognosis. I wanted to know if I have time to undergo a surgery or my days are counted. Also, I was in severe pain. She asked for the medicine box and got to know that I was consuming the wrong dosage. Probably, with my constant questioning and complain the doctor got impatient. She snapped at me saying ‘from next time sister will be visiting you’... ‘She was very angry and did not drink water too, may be had some problems at her own house.’ On the other hand, the nurse later shared that the doctor is usually nice but Ravindaran was extremely impatient and the doctor had to loose her cool.

In another centre, the team was unhappy with different doctors showing up on every visit. They felt that this hampered patient’s trust and did not provide a fertile ground for establishing doctor-patient rapport. The teams of counselors and nurse were closer to the families. In one such case, the counsellor was angry with the doctor’s decision. The team had visited an eighty two year old bed ridden patient who had bone metastasis and couldn’t speak due to senility. The family hails from an upper economic strata; the patient is a retired professor of literature at Delhi University while her only son is in public administrative services. The family is advised by a leading private hospital for chemotherapy sessions for the patient. The counsellor is displeased and agitated when the doctor from the organization suggests them to go by the advice of the hospital. The counsellor shares, ‘You work in the field of palliative care and then advice for chemotherapy sessions in case of such frail people who lack any strength to bear another dose. This is outrageous and makes me very angry! At least the doctor could have spoken her mind and shared some of the negatives of chemotherapy given patient’s age and her condition. She could have involved the nurse and the counsellor in her discussion with family. The patient is not in a position to sustain one session and you know how private hospitals are like! Moreover, how will you be taking this patient to the hospital with bone 'mets' (metastasis) and her inability to stand and walk? '

Since I knew the doctor, on my next meeting I asked her about this case citing the family's concerns. I had visited the family before meeting her and therefore, framed my questions so that she does not come to perceive my question arising from team's displeasure but family's confusion. She shared her perception,

> "We are not from hospitals, we work in an NGO and therefore, especially with elite clientele, it can be tricky to make them understand. Had I said a no and the patient would have passed away…it would have gathered a lot of blame. I do not want to take any responsibility, in this sense. I have experienced that certain families' look up to oncologists more than us, the general practitioners, and have more faith in them. We are not 'cancer ka doctor' (doctor's specialising in cancer treatment). Once we went to a very rich and seemingly educated household, they asked my qualification and when we said we provide palliative care and are not oncologists, they snatched patient's file from my hand, literally snatched it. Can you believe it? I am a 'woman' and my field area is very different from a clinical setting. I need to think and speak accordingly. Across economic strata the patients are equally difficult as there is a lack of awareness. Often when the patient is in gasping condition and in a lot of pain we provide sub-lingual morphine so that patient goes away without pain. But there have been incidents when families blamed us for the death of the patient. They were agitated and could have harmed us."

After three months, I saw patient's family at the bereavement meeting held for families who lost their loved ones in that year (2013-14). They had decided against chemotherapy, as the counsellor and the nurse suggested them in doctor's absence. Her son shared that after talking to the counsellor he 'did not feel that his mother should undergo such a strong treatment and more so when the disease has already advanced beyond control'.

> "We are educated people, but it helps to communicate. He saved our mother from unnecessary discomfort."

The doctor's apprehension in the above case are based on personal assumptions as another lady doctor from the organization did something contrary in a similar situation. An elderly man from an elite household living in the Delhi suburbs (the suburban area) was diagnosed with the cancer in 2007 but his condition deteriorated last year (2012). He received blood transfusion for six months but in the month of March (2013), the family decided to stop anymore transfusions in consultation with the team. In my visit, the middle aged son reconfirmed his decision with the doctor and the nurse. The doctor assured him asking for the nature to take its course and not aggravate the suffering as transfusion requires pricking and is painful for a patient who is 'very bony'. The nurse added that it would be difficult in such patients (bony) to find vein and every time the patient needs to be moved to the hospital as he is unable to walk by himself. The family added that the patient had pain every time they touch him, which the doctor referred to as 'touch pain': a characteristic pain in some patients with multiple myeloma.

> "what doctors need to be helped to master is the art of acknowledging and affirming the patient as a suffering human being; imagining alternative contexts

> and practices for responding to calamity; and conversing with and supporting patients in desperate situations where the emphasis is on what really matters to the patient and his or her intimates. A programme of medical training that makes this happen, however it is innovated, should combine practical experience of caregiving for health catastrophes in homes and institutions, where students actually do those things that families do, with the knowledge basis that stands behind the art of medicine, and that means interpretive theory and methods from humanists and social scientists." (Kleinman, 2008:23)

The above citation reminds me of an interaction with the young interns/junior residents from the pain clinic AIIMS were working on different aspects of social lives of their cancer patients, like spirituality and diet, and how it impinges upon their health. During our interactions in the OPD, where I used to observe the surroundings in an OPD, they were often seen holding a questionnaire and asking their patients certain close ended questions. During this exercise, some familiar faces amongst the patients were also seen; they introduced me, on their part, to these young medical students saying 'this doctor comes to our place often'. One intern immediately asked 'You go to their houses? Where are you doing your residency from?' When I told them I am not a doctor and I was doing exactly same kind of 'observation' here as I used to do at their place. Some of the young trainee doctor's observed these interactions and spoke about not their inability to meet patients at more personal settings. As one resident shared,

> 'We do a very technical kind of research without even knowing the patient as a person and barely knowing his/her family. That possibly is the key reason they are a little hesitant while talking to us and then they are aware we are 'doctors' here!

> The only feedback we rely on is from the organization; while we do not have a follow up mechanism we know the patients are being taken care of.'

Palliative care: A retrospective account of a nurse

Sister Anam is a soft spoken nurse working in one of the out-patient facility. A little reserved, she took some time to open up with me and share her story. During an engrossing conversation where the counsellor was sharing some of last moments in her patients' lives. It was during the lunch time and there was only one patient taking rest in the other room. We were sitting in the doctor's room for lunch as it has a huge table for all of us to eat properly. The doctor leaves by two everyday for she wants to spend time with her husband who stays at home post-retirement. The doctor has chosen to work from the out patient facility and not with the teams for a multiple reasons. She finds it comfortable for her age to sit at one place and see patients. Since her husband has retired, she wants to give time at home and it will not be possible for her to do so with the home-care teams. Nevertheless, she shares she likes her work in its present form instead of her experience with the home visits for one has to visit all kinds of homes and eat inside the vehicle. We share the lunch with the counsellor and the nurse along with two other staff members and the nurse's young niece who has come to visit her aunt during summer vacations and comes with her for the clinic where the doctor helps her with her subjects. The doctor brings her help's daughter too and both of them study together. They do their work quietly as the patients pour in and whenever the doctor is free for sometime, the two girls discuss their problems with geometric equations and algebra. Coming back to the nurse as she and the rest of us listen intently to the counsellor who is sharing with me many of the last moments of the patients and their families and the need to be able to say final goodbyes. As the counsellor finishes her stories, we have finished our lunch. The nurse instructs her niece to sit quietly in a corner with her books and we wait for other patients to arrive, she sits by my side and initiates a conversation adding how her training with the organization prepared her for something she did not think about.

She states that her work draws no similarities with her training as a nurse in the hospitals. She has worked in this facility as well as while travelling with the team and her experience was never similar to her training in the nursing school or later when she worked in private hospitals. Explaining her first experience of dressing a cancerous wound, she shares that it was the most difficult wound she ever saw and intervened with. It was a cauliflower wound[16] on the mouth of the patient with the molars falling out in her hands as she tried to clean it for dressing. She thought to herself why she was doing it in the first place but later convinced herself that it was merely a kind of dressing. The most important difference in this wound and 'normal' wounds was the fact that it was of a non-healing kind and fungating too. Unable to express verbally she keeps her hand close to her chest and shares that such growths are horrific and churn your insides. She shares that now she is used to such a sight and doesn't think twice before dressing it.

She finds working in palliative care as emotionally indulgent unlike the usual medical practice, which she was earlier a part of. She shares that the normal medical practice lacks emotional involvement. Over the years, she has wondered over her nature of work

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[16] In the field many people were living with such wounds. For a nurse or an onlooker it can merely be a displeasing sight. But these tumours growths influenced the notion of body, hygiene and death and provided ground for shame, stigma, pollution and abhorrence. I shall be discussing more on such experiences in later chapters. Also, the internet describes such wounds as crater-like wounds, commonly called ulcerating lesions, have high edges with a sunken centre. Cauliflower-like wounds, referred to as fungating lesions, look like clusters of raised nodules growing above the surface of the skin. Both ulcerating and fungating lesions can appear in the same wound bed.

every day while dressing multiple wounds, using suction method to clean the tracheotomy tubes and listening to the sounds of the deposited phlegm, listening to wailing patients and bereaving families. She found her answer when her mother was diagnosed with advanced cancer. Trying to control her emotions she shares that she misses her mother's presence in her life but credits her experience in palliative care that enabled her to come to terms with her mother's terminal diagnosis and helped her mother with a comfortable exit. The day her mother was diagnosed with cancer, she shares that despite being emotionally torn she could clearly see the reason behind her calling. She is visibly shaken while narrating her association with palliative care but keeps smiling in between trying to overcome the restrain in her voice and says that listening to the counselor's stories reminded her of her mother again.

The above story shares the value of work for a palliative care nurse and the interpretations of her life events trying to configure the dilemma of experiencing suffering both professionally and personally. This process of unintentional interpretation of meanings to cope up with the loss as well as come up with validations to the self for working amidst death, dying and suffering are similar to many other palliative care professionals. Despite the impinging financial needs and desire for increased salaries, the care professionals share anecdotes and experiences while speaking about their motivation to work in an emotionally challenging environment. Many caregivers confide that the motivation comes from peaceful endings. But there are always exceptions to the rules, one of the team members once shared that he had to admit to all the 'preachy motivating talk' for the reasons of compliance and not wishing to demoralize his fellow team mates but he looks at it as 'any other profession to earn his bread and butter'. He keeps in touch with me till now only to share his opinion on the issues lack of health reforms, stringent opiate rules, pain management in India, the politics of the big pharma and private hospitals, the efficacy of qualitative research in the field of health, his opinion on the neoliberal markets and free markets and the need for a universal health care system. While he may never share any personal inspiring stories yet he remains motivated to engage in issues related to patient care.

Is there a need for palliative care?

Palliative care is about symptom management and emotional support at all points of life beginning from the time of diagnosis of terminal or life limiting disorder. The reasons cited for its general absence within our national health care systems especially with reference to state supported health care services can vary. Those within the palliative care often address it as lack of concern, indifference towards those who are no more ‘functional’, lack of political will and also a sort of digression given that India faces a lot of challenge in order to combat with the load of infectious diseases, basic issues like maintaining sanitation and hygiene, malnutrition, mother and child mortality rate. Laying focus on the debilitating and dying is important given the statistics which demonstrate an ever increasing burden of non-communicable diseases in India. With increased life span and a growing number of older populations, the society needs to prepare itself for establishing support systems providing care. But it is the cultural viability of palliative care needs to be explored and understood in order to see it as the only way of providing care. One of the staff members from the helpline narrates a call from Dehradoon where the caregiver desired to know about palliative care options around his area. She could not hear the caller clearly as the patient was screaming aloud in pain. Hearing this she asked the caregiver to call a doctor and seek immediate relief for the patient first to which he replied that they lived up in the hills where the doctor would not come as the distance can only be covered on foot and takes almost an hour and a half. In ‘normal’ sickness they walk down to see the doctor but the patient is not in a position to walk and they may have to use a palanquin to bring her down. In such conditions, had there been a dedicated team visiting people in far off places as is the case with Delhi it would have been of much help. She stated further, “we come to your house to suggest you ways to keep the patient in comfort and that too for no charges, why the resistance then?” Her colleague in the helpline answers her question citing trust issues and transparency with the way NGOs’s function in our country. She further suggests that people are not aware of the consequences as a disease progresses and there is a lack of awareness among the masses which is aggravated by minimal publicity on the part of the organization. The callers often treat them as ‘punching bags’ especially the elite clientele who demand an immediate visit in the situation of a crisis presuming the organization runs ‘air ambulances’ (speaks in a satirical manner). In many cases, the families call for guidance but are not interested in team visits stating that the patient is not bed ridden yet.

In such a situation, the main focus of the organization is to provide pain relief. The organization has a history of struggle for procuring license for morphine distribution. Often called by the staff members as ‘golden drug’, the first visit to a patient house was most often made in order to alleviate pain of the patient. The patients deafening cries were often a reason for the neighbours or the landlord to approach the organization. The role of Organization was spread through word of mouth in many cases. During the unbearable bouts of pain, patients would often beg for relief. Some expressed their wish to die instead of bearing up with the pain. But after the medication, they would change their decisions. Strangely, India is the leading exporter of morphine to other nations especially from the developed world yet Indian patients are unable to access it. In states of Delhi, Kerala and Tamil Nadu, the patients have easy access to morphine. But people in many states of India are still deprived of their basic right to live without suffering. The case cited above is from the hills and strangely in other northern states like Punjab (Advani 2013) and Himachal (Charles 2001) a large number of youth populations are facing drug addiction despite the stringent drug laws. Whereas the Indian state remains indifferent to the patients who remain deprived of a pain free life. The organization got in association with health care staff of a public hospital in Punjab for providing training of palliative care to their staff members. Punjab is facing an alarmingly increased incidence of cancer[17] also. The under-training staff from Punjab came to Delhi so as to develop a closer understanding of palliative care. Some of them used to join the teams I was working with. The major concern they shared was with the delivery of morphine. As one of the nurses shared, ‘in our state it would be difficult to manage the menace of drug addiction as many young people in the families are addicted to opium husk’. Her fears well placed, the irony is the fact that Indian state makes laws for illegal trade of drugs and these are still rampantly traded. Yet the patient care is at stake with no universal provisions for drug control.

During the IAPCON 2015 at Hyderabad, two anesthesiologists were found interacting over the issue of pain control. While one was from the government college

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[17] http://www.appcb.ap.nic.in/faq/punj.htm (Last accessed in 2013)

Secunderabad the other was a general physician Scotland. The Indian doctor shared his lack of awareness over the administering and usage of morphine listening to which the Scottish GP asked him assuming that they ‘at least’ must be using it while performing ‘laparotomy’ (a surgical procedure involving a large incision through the abdominal wall to gain access into the abdominal cavity).While he answered in negation, she turned towards me making a horrifically contorted face and was bemused. He asked her whether they use it in UK? She replied with an “of course”… “Day in day out” and smilingly said, “I am sure India must be exporting it to us”. After the conversation was over, she turned to me saying,

> ‘I totally see an anthropologist enjoying our conversation but I am amazed they don’t use morphine. We give it to our patients as many times as possible just so that they do not have to suffer from unbearable and undesirable pain. How appalling! This is cruel.’

I told her that in many states the doctors often suggest fentanyl patches (a transdermal patch) to which she retorted saying ‘a fentanyl patch is very effective but needs to be frequently changed and not everyone can afford it whereas morphine is much cheaper and affordable.’

In the course of my work, I met many households witnessing their loved one in excruciating pain. The teams however, were able to handle it but often had to face resistance due to a lot of misconceptions and fear of addiction. Later, as one family shared, ‘such a medicine which puts him to good sleep everyday cannot be bad, we have seen him unable to sleep for close to a month now and we could not sleep either’. At the time, the family member was sharing this account she had trails of tears streaming her cheeks. She was talking about her son; he passed away after this meeting. When we visited them for bereavement she shared that the entire neighbourhood along with the family has *'tassalli'* (assurance) that he was not in pain when he left them, 'it was a peaceful death and a relief from the pain'.

Palliative care teams in the local context, work a little differently than their counterparts in the west. The literature on palliative care shows a strong focus on the team members. The next priority is attributed to bodily concerns. The organization, during its workshops and meetings, stresses upon similar aspects too but the home care teams work through a local understanding which comes from visiting the houses of patients and witnessing their living realities and their struggles not only with the disease but with the domestic concerns of any household. This intimacy creates a space for newer meanings of care, negotiations and manipulations. As I explore and situate the findings through an anthropological lens it renders the study a scope to look beyond the concerns of palliative care researchers who focus on the design and delivery of health services and the management of bodily symptoms (Kellehear 2007:372). I begin with an illustration of care practices in the next chapter to understand the multiple meanings of care as it emerges in the everyday lives of people interacting with cancer.

3. Understanding care

> "…..caregiving is envisioned as an existential quality of what it is to be a human being. We give care as part of the flow of everyday lived values and emotions that make up moral experience. Here collective values and social emotions are as influential as individual ones. Within these local moral worlds—family, network, institution, community—caregiving is one of those things that really matters, but usually not the only thing. Contestation over what matters most figures importantly in how care is organised, provided, received, and evaluated. Interpretive perspectives on the process of giving and receiving care lead medical humanists to reflect on local patterns of moral life that give rise to criticism of interference with caregiving, resistance to local forces that cause such interference, and perhaps most remarkably efforts to transcend local values so as to aspire for ethically more promising and enabling ways of living through catastrophe." (Kleinman 2008:23)

The ingression of the extant palliative care services within the peripheries of home attribute mixed meanings to care. As care practices influence the notion of well-being amidst the routine struggles with the debilities and disabilities in the lives of cancer patients, I propose an anthropological inquiry to grasp the modalities of emerging care frameworks within the families. The intermingling of personal and professional boundaries raises interesting differences between ethical and moral codes of care practices for what may be locally understood as moral may not subscribe to the medically presumed ethical. As we shall see in the chapter, care involves multiple negotiations based on choice, on hope, on beliefs, on inequities, and on the collective as well as the individual performances. The domestic means of addressing the symptoms, bodily and otherwise, generate a complex relationship between the material actors and the semantics of care practices. I analyse these details at a micro level by sifting through the socio-economic, spatial and temporal realities of the people living with cancer and those caring for them so as to understand the constituents of care. I begin by offering a sketch of a typical home visit session and explore the concerns that permeate the local worlds of my informants in which seemingly tacit aspects of their care practices come to the fore. I do so at the risk of drowning the reader in tedious details, though it is the very mundane repetition that most importantly characterises these daily concerns/activities.

Let us call her S. She has a radiant glow on her cheeks. She has neatly side swept short hair of the size that covers the scalp entirely. She is sixty nine years old, stays with her son and his wife and two grandchildren in a government housing society. Her daughter lives in America. She has cervical cancer for which she underwent radiation therapy almost eight months ago. Her cancer hasn’t stopped growing despite these measures. She has developed a wide fistula due to which every time she passes the urine she cringes in pain. The nurse, assuming my lack of awareness, explains to me that ‘fistula is created when the tumour ruptures creating a bridge between the passage of urine and stool, allowing the two to mix up thus causing ‘unimaginable’ pain and burning sensation’. As the nurse checks the fistula, she smiles and says, ‘aunty is very hygienic’. I am new to the field and assuming my role of a researcher I stand at a distance allowing the nurse to carry out the physical examinations which includes taking note of blood pressure, checking the mouth for oral hygiene, looking at the compressed areas of body for any bed sores. I am told that she is bed ridden for a year now as the nurse touches S's legs and gestures to me her inability to walk. In the meanwhile, the counsellor whispers in her ears asking her about the daughter-in-law and looks at me gesturing to stay quiet by bringing her finger close to her mouth. S points her finger towards the bathroom and the counsellor gets it. I assume a tension in her relationship with the daughter-in-law. Then, the counsellor asks S what did she have for breakfast? She, for the first time in my presence, speaks in a disruptive fashion as if trying to recollect her morning meal. It is 10 am by the wall clock. She says porridge and then speaks something incomprehensible '*badam*'[18]to the nurse and the counsellor and both of them ask again. She tries to explain and I come forward and tell them that she had jaggery and groundnuts too. She speaks to me in Bangla asking if I know the language, I express my inability to speak and tell her that I can understand a bit of Bangla. Then she asks me to come forward, holds my hand and kisses it, smiling all the while. The nurse and the counsellor introduce me as a student who is here for 'study purpose'. She tells them that I resemble her daughter who lives in America. Then she shares with me that she wants to eat fish curry but she is served boiled food and waits for me to answer. I smile sheepishly looking sceptical and the nurse comes to my rescue suggesting that she will ask the maid and talk to her son to serve her fish, but with very less oil and spices. S makes a face but nods her head in

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[18] In north India, groundnut is called as '*moong-phali'*whereas in the north eastern part of the country, it is often called as '*badam'*, a term used for almonds in northern India. The nurse and the counsellor are from Kerala and unable to make this distinction.

acceptance. Her maid comes and brings orange juice for her as well as for us. S asks is we would like to have tea which we politely refuse. Her interactions are largely silent and more gestural (using her hands and facial expressions). In the meantime, the daughter-in-law who has just taken bath arrives and greets the team. The team introduces me again. The team asks her if S is made to sit in the sun as its cold (December, 2013) these days. They suggest her to eat fish and the daughter-in-law says that S is too picky for food and has no control on the taste buds. A spicy fish curry can lead to an upset stomach and already for the last three-four days she has been unable to ‘control’ her motions, thereby soiling the bed. She further adds that yesterday there was foul smell in the room and the children do not like it.

All this while, S has been holding my hand while looking down as if absorbed in her own thoughts. In the meantime, the nurse takes the empty glass from my hand and moves towards the kitchen, the daughter-in-law follows her leaving us alone with S. Suddenly, the counsellor begins to comfort her by rubbing her shoulder. S’s eyes are rimmed with tears, with shivering lips she states that she had soiled her diaper and her clothes after she was bathed by her son. Her son had to wash her all over again and change her diaper. He was late for his office as he did it alone. The maid had not arrived till then and his wife doesn’t like to touch the dirty clothing. She keeps crying while trying to speak and shares that she feels very sad for her son, who is managing her medications, hospital visits and all her washing and cleaning by himself. She expresses her wish to die. The counsellor listens to her and asks her if she did the same for her son when he was a baby unable to take care of himself. To which S confirms by nodding while saying ‘but he was a child’. She says that she is an ‘old woman’ and it is difficult and shameful for her son to see her naked and dependent for her private needs. The counsellor begins to praise her son adding that even if the daughter-in-law wouldn’t help much she never intervenes between her relationship with her son. S acknowledges this by nodding her head in affirmation and adds that the daughter-in-law is never mean to her. S asks me if I would be revisiting her, the counsellor answers that the head office might ask me to join some other team. I interrupt by asking her if she wants to talk about anything she can share with me. She expresses her resentment over the ‘dirty disease (*gandi bimari*), no enemy should contract it’. She adds that it is better to die than to live with pain and living a shameless life. I ask her what if she had to care for her son or her parents or her deceased husband. Tears well up in her eyes adding that she feels helpless. It is time for us to leave, she asks me to come closer and this time plants a kiss on my cheek. I am a little bewildered with such a strongly intimate expression in my first visit and try to obscure my dilemma with a smile and kissing her hands in return.

As we descend the stairs on our way to the vehicle, the team expresses their delight on S’s acceptance of my presence saying that she has not opened up with them to such an extent even after visiting her for four months, probably she could associate me with her daughter and they ask me to join them again on the next visit. They explain to me that S and her daughter-in-law haven't been getting along well after she was bed ridden. Her son tries to keep things stable at home by taking care of the needs of his mother, employing maids for the assistance of his wife for domestic chores in his absence and staying in touch with the team as much as possible. They suggest that the daughter-in-law is not an ill willed woman. The nurse shares that, when she left us with S, the daughter-in-law shared her concerns regarding pain medication for S. The daughter-in-law believes that the dosage that was changed last week could have led to an upset stomach, also she keeps a watch on S at night as her husband needs to sleep and has found that the pain medication is only effective for a short duration after which S can be heard wincing in pain. The counsellor adds that not everyone is comfortable in doing all kinds of care work and people can dislike cleaning and washing of soiled clothes and bodies often. Moreover, the daughter-in-law takes care of the household as well as of her two school going children and the team believes that her husband is cooperating with her in handling care responsibilities and for the rest they are able to afford maids. She further shares that in many of their home visits they have found that the ‘sons of the house would never do such tasks, not even the daughters of the households in some cases and it is the daughter-in-law who is obliged to carry out such work, but no one judges these men or women given their relation to the patient’.

The above account raises a bunch of issues ranging from role of gender in care practices, hierarchies in social relationships, what constitutes care, what defines good and bad care and the notion of paid and unpaid care. This account throws light on the interactions and experiences of the team members with the members of the household and how a shared understanding of multiple aspects leads to emergent meanings of care. In addition, the S’s case highlights patient privacy as well as concern over dependency and the accompanying shame, pain and its management, social relationships between the sick and the carers within a family as well as issues related to purity and pollution and we talk about the disease and its symptoms, the physical challenges it presents the patients and the families. Ironically, in the field attributing to a modern understanding to the disease the explanations and expectations begin with a strong reliance on the clinical aspects of care and hospitals are seen as universal nostrums. Disease, on the other hand, presents a bigger challenge to the people who live with it. As I observe the disease of cancer it gradually brings an array of symptoms right from the time of diagnosis. The patients locate an ulcerating, non-healing wound or experience pain and debility, or a small knot-like painful structure (referred to as *gaanth*), try to heal it through local quacks, visit traditional healers and in some cases sorcerers, and then visit a hospital or directly visit the hospital on their own or are accompanied by their families, they undergo tests, share their anxieties, avail treatment options, undergo surgical interventions or chemotherapy or radiation therapy, increase intake of nutritious food, take precautions while cooking the food, depend on others, both human and non-human actors for toilet needs and bathing, medications, dressings, wearing clothes, making beds. They require support from their families. The common string that binds these issues together is 'care' and it goes beyond the clinical interventions, I intend to explore the same in this chapter. Of lately, a large number of studies have emerged within the discipline of anthropology which focus on the concept of care in different contexts. Why as anthropologists we need to talk about care; in the current context, care of the dying, of the ailing, of the weak as well as of those who are providing care? When we talk about care, do we need a theorisation? Is it a plausible option or do we need to delve into the practices for exploring the process of meaning-making? The anthropological accounts of cancer either lay emphasis on individual patient experience based on narratives or in the light of institutional positioning of diagnosis, treatment and prognosis and overall knowledge of the illness experience. This chapter derives its understanding from both the positions and intends to talk about the sociality of care. Care does not enact itself in vacuum. It is enmeshed in the social and moral world of the patient and her family. I argue for the expansive nature of care and the subtleties which define and demarcate this expansion. The anthropology of care concerns itself with the very expansion unlike clinical care which lacks an intimate ground for a holistic performance. Clinical care is about diagnosing, treating the ailing organ or body, being interested in the focussed listening while cutting the long story short and guiding through prescriptions. I attempt to explore the plausibility of the conceptualisation of care by the end of this chapter.

Palliative care is a specialised care, a mixed care (Fine 2005) i.e. it involves community approach and seeks contribution of different stake holders (state and civil society). In order to explore questions related to its need and the meaning it renders to the 'cancered' reality of those in their last days, it is of utmost importance to have a comprehensive understanding of care as a concept within sociology and anthropology. Fine (2005:261) calls care a necessary social response to bodily vulnerability and a foundation for the patterns of social solidarity that underlie human societies. Care is a process of interaction (Mol 2008) and if one sees palliative care as a specialised form of care, because of its incorporation of knowledge and practice from medical corpus, it can be viewed as an interactive process too. This interaction has consequences on the everyday reality of people engaged in providing and seeking care. Different disciplines have configured care as per their contextual understanding. The concept of care is problematic in sociological research and has different meanings for different researchers which lead to a partial understanding of society's caring activities (Thomas 1993:664). Care within sociology is often described as a generic category, when it is specific to public and private domains of human life, with an unclear epistemological status (ibid. 650). The author cites the critique of ‘home-based kin care’ which is rarely acknowledged and is contingent upon factors like age, gender, relationship status. Also, he suggests that the home-based kin care does not guarantee good care as in many cases familial care can be devoid of love and affection and can be abusive too. In the present research, palliative care is largely dependent upon the role of family members and can be used to explore the domestic care practices as well. The limited research in sociology and anthropology shows that care is badly rewarded because of its gendered conception and is often associated with the women of colour (England 2005). Fine (2005) dismantles the notion of care as a taken for granted behaviour and refers to different models of care especially the one where a combination of formal and informal care, called as the community care approach or mixed care, is used in practice. Such a model links micro-interactions to macro structures (ibid. 249). As per the author, a sociological interest in care must manifest interest in larger processes of social change and their effects at the level of personal experiences. This can be achieved using an interactive approach which focuses on the way care is organised. The phenomenological[19] questions addressing care and the perception of body are of great use to corroborate a social understanding of care. Mol et al. (2010) on the contrary, deconstruct the prevailing notions of care and address the need to understand care as a practice with its ever changing imagery contingent upon the site it is being practiced at. Within the health care industry, the positions of those who are at the receiving end of care have always been precarious (ibid. 9). The analysis boils down to

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[19] “Phenomenology must not be thought of as a method but a philosophical paradigm within which methods are chosen and subsequently questions are framed. The strength and weaknesses of this method lie in rigour of its application than in the chosen method of data collection. A phenomenological research is an inductive approach and is more likely to descriptive accounts and interpretations reflecting day to day experiences and practices in a particular context”. (Seymourand Clark 1998:127-131)

putting something right which is failing. The receivers (or care seekers) are allegedly passive with lack of power and they are condensed into a term 'patient'. Mol (2008) tries to shift the passive position of patients by calling them active consumers who are involved in taking care of themselves by attending to their symptoms. Mol et al.(2010:10-11) stress on a need to strengthen care practices, for which verbal descriptions may not suffice as care is mostly unspoken. In such a case, patients and practitioners are actors involved in carrying forward a practice to be explored and understood as good or bad through ethnography. Is there a good or bad care? Can care be ambivalent and how? The authors suggest that good care can have bad effects and hence, the locally relevant 'good' and 'bad' despite being surprisingly obvious might not be the case in reality. The interaction, as must have been assessed by now, is channelized through a network comprising of two groups; the care givers and the care seekers/ choosers[20]. The interlink-ages within and between these groups are sustained by (a) professional responsibility (Saunders 1996), (b) familial responsibility often guided by emotional, moral and religious value system (Clark 1993 b) and (c) the relationship between "self, body and the social situatedness" (Searle 1995). These interactions are guided by a consciousness to evade or cope up with the fear of 'death lurking nearby' (Berger and Luckmann 1969) which appears incomplete and parochial as the field

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[20] Care seekers are referred to as care choosers by keeping Mol's (2010) perspective of alleged passivity attributed to the term 'patient'. The group of care givers can be further divided into two sub-groups: the formal care givers (members of palliative care teams as well as other key players having a stake in palliative care discussions) and the informal care givers (the immediate family or friends who take care of the patient). The group of care seekers comprises of patients suffering from cancer and the bereaved family members. It is important to note here that the group of informal care givers often need counselling while awaiting the death of their close one and need bereavement counselling once the family member is dead and therefore, the external structure of this group remains the same. However, their responsibilities and experiences are constantly at flux. In a way, informal care givers oscillate between the roles of care providers and care seekers at the same time.

exposes care not only through the notion of mortality and anticipated loss but the notion of choice and hope emerging as key components in the lives of people living with cancer. Also, in the 20th century, within the anthropological discourse, care has been seen as an 'other' to technology (Mol et al. 2010:14-15). As per the authors, the two have been pitted against each other with one being nourishing and a "gift in the Maussian sense" of the term while the other being instrumental and an "intervention". However, technology can be a boon or a bane depending on its usage and therefore, can have generous contribution to caring practices. The present study offers a fertile ground to explore the relationship of care and technology within palliative care. Interestingly, the everyday activities like taking bath, worshipping or joining rest of the family at the dining table (especially in the case of those who undergo surgical procedures like colostomy), sharing a bed with the spouse and an intimate encounter raise the issues related to purity and pollution. If one renders a socio-cultural perspective to the practice of palliative care, it can also be approached as an enquiry holding meaning in the lives of the terminally-ill and thereby, directing to questions relevant for the functioning of society amidst such occasional disruptions. Palliative care, as suggested by its advocates, is an action to settle the chaos and uncertainty synonymous to cancer (Sontag 1990). Mol (2008) argues that good care has to do little with the patient choice and therefore creating more avenues for the patient to choose from is futile. The author sees care as a process where the care-giver keeps trying without being driven by the market logic and hence, in a supposedly resource poor country like India care appears a more plausible choice in comparison of seeking cure especially in the case of those diagnosed with advanced cancers, which is a majority (as mentioned earlier). She concludes that good care is not a matter of individual choice instead it originates from persistent efforts to bring knowledge and technology based interventions closer to the diseased bodies and complicated lives. Giddens (2005) perceives care as ‘a burden’, for physicians turned anthropologists it’s a clinical skill (Kleinman 2008, 2010). Under different cultural codes, care is often considered as ‘dirty work’ raising the concerns of purity and pollution not only of/for the patient but the carer too (Fine 2005:257). Alber and Drotbohm (2015) combine and classify the work of different anthropologists into three sections where care is understood as work, as kinship and care as life course. The feminist theories and neo-liberal marxism distinguishes care as work based on paid and unpaid labour and perceives it as a commercial and professional activity. The Society for Cultural Anthropologists came up with a series on the theme of care in the year 2014[21] in order to explore the contribution of the discipline to the study of care. Four scholars contributed to this series (Field notes: Care) and raised pertinent questions. Yates- Doerrr (2014) argues care as provocation where the practice raises questions related to the context of the origins of care and subsequently asks if we can possibly write about care without giving in to dictums of the universal laws in the discipline? She cites her own fieldwork in Guatemala on obese people where clinical interactions were limited to the prescriptions and questions related to weight gain and dietary histories. She distinguishes the anthropological interest from clinical interest by citing the instance of a clinical query, in the case of obese patients, where clinicians never enquired about land or trade agreements where food was cultivated. As per her, such an enquiry would have resulted in widening the ambit of care but the clinicians’ interest remained confined to the bodily issues. She, thus, lays emphasis on the ever changing

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[21] Richards, Fayana. "Field Notes: Care." Correspondences, Cultural Anthropology website, March 17, 2014. https://culanth.org/fieldsights/498-field-notes-care

contexts of the field of care and its expansive nature. Heinemann (2014) looks at care as a deviance by observing people undergoing organ transplants, following procedures by consuming regular dosage to avoid organ rejection and simultaneously working to make their ends meet. She draws from the Ingoldian (2011: 69-70) perspective of life where the lifeworld is an entangled mesh of "growth and movement along which life is lived". This resonates with my field findings where people often reasoned there struggles (for an outsider) as "things you have to do to put up with life anyway". Fitzgerald (2014) talks about care as a process of translation where observations keep shifting, a written text becomes an account of the observed but a field for the reader and in a similar fashion when the carers become patients the subtle nature of the shifting seems mundane yet intriguing to an anthropologist. Similarly, Taylor (2014) explains care through the process of integration of disparate activities with their own local logics and dismisses the segregated understanding of care either as a burden, or an emotion, or a moral obligation or a matter of 'dirty work' (Jervis 2001). Instead it is what Mol (2008) suggests, a tinkering, an intervention striving to bridge gaps. Arthur Kleinman (Taylor 2014) shares the work of different anthropologists to explain this process of integration as,

> "Care is, in this sense, a "critical sociality based on incommensurate experience" (Garcia 2010:50). Indeed, it is as a response to this "acknowledged, structural inequality between caregivers and care-receivers" (Livingston 2012:166) that the care has moral force. As "a brave and noble response to the shared human condition of being both mortal and compassionate creatures" (Taylor 2003:175), caregiving is "a moral practice that makes caregivers, and at times even the care-

> receivers, more present and thereby fully human… even as we experience our limits and failures…"

I principally combine the four understandings in the form of field work notes and explore the politics of different possibilities of care. Care is a tacit feature observed widely in the animal kingdom. The tendency to care; be it for the sick or dying, for the self, for others from the herd or outside the herd is observed across the animal world, primates as well as non-primates. Primates, both human and non-human, express some form of care, varying from grooming behaviour amongst non-human primates to licking of wounds and eating grass among other mammals (Buettner-Janusch 1969). If seen this way, care can be understood as a biologically driven urge for a sustained well-being of a species. In human societies, care is extended not only to the members of its own community but to other animals too[22]. For instance, pet owners, cattle farms, and wildlife conservationists' etcetera. Care, in human society, is witnessed in the simplest everyday gestures like helping someone cross a street, tending the plants in your kitchen garden or in the fields, offering food and shelter to a traveller, preparing the school bag of a child for the next day, holding hands while walking on roadside. All such gestures can have varied meanings in varied contexts, however, the gestures reflect some or the other form of care. Care in human society is a complex behavioural attribute with possible linkages with wider structures of a community life. The kind of 'care' to be discussed in this chapter, argues for an understanding based on the observations of everyday lives of sick people and the ones who tend to them, within a set of institutional boundaries. The boundaries are professional and personal as well as paid and unpaid. The interplay of these

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[22] http://www.transcript-verlag.de/media/pdf/39d197aa7f5ff189d2ab3eadab101bed.pdf

boundaries is not mutually exclusive which for instance implies a professional and paid care is not a strictly defined category and has fluid boundaries so that the personal often intervenes with the professional. Similarly, unpaid care can be distantly personal and therefore, obligatory in nature. The chapter looks into these interstices and weaves a socio-cultural narrative of everyday care at the end of life. The purpose is to propose a body of work that tries to fill inadequacies in ethnographic understanding of various aspects of care practices within the Indian context. I choose to do so through a limited access in the families caring of cancer patients and their association with the palliative care team members.

The Indian healthcare system awaits stronger provisions for long term care of different groups in the population; the non-governmental organisations raise the issue of 'increasing burden of non-communicable disease as well as old age related debilities in the forthcoming decades'[23]. With an increasing number of old age population as well the patients with life-threatening and life limiting disorders, given the advancement in medical technology to keep people alive, the threat of lack of care looms large. Our own personal experiences, thus, are prone to have an impact on our judgment of situations where others are providing care. Also, the international and national aid programs in association with the developed world as well as the elite circuits in the country are increasingly creating framework in which "care" is to be understood. This poses the threat of understanding and presuming the notions and values of caregivers to be similar, given that the over-arching providing structure is guided by same values, perceptions and intent, creating a culture of care.

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[23] http://www.icmr.nic.in/annual/icmrhq2004-05/Non-Communicable%20Diseases.pdf

> ‘And from foreign perspectives, the struggles that accompany family care are imagined as a burden with particular emotional valences requiring a host of supports.’
>
> (Aulino 2012:20) in her unpublished doctoral thesis mentions ‘foreign’ as against the Thai understanding of caregiving.)

Within the anthropological literature, caregiving is explored as a moral import (Jervis 2001), as a provider’s trope amidst neoliberal reforms (Mol 2008), as a mode of survival within the structures of inequality, state failure and epidemics (Fassin 2007) and a thriving ground for hope (Mattingly 2012). Annemarie Mol (2002, 2008) discusses the situated-ness of care by proposing to understand care within a context, not by generalising but by looking into specifics, for instance in animal farms, in the market, in pathology labs etc. Similarly, if one tries to understand care in a hospital or a clinical setting, it is situated within the human body. In the present work, care can be situated in a home based setting but via multiple agencies. The first being, through the home-care team which situates care within the human body as well as outside it: within the conversations, in tacit physical gestures of comforting by touching and listening intently. The second through the family members/ friends/ primary care givers who situate it in their relationships with the patient as well as through their roles and responsibilities within the family. The third is through the self. In case of the self, the care gets situated with the ‘personal’ and becomes a disciplining action for one’s own body and acquires agency to demonstrate body control, negate dependency and develop a sense of ‘normal’ while diseased or experience an on-going transition of the identity. The chapter looks into stories from the field which elaborate care in this very essence. Since all these sites of situating care are also acts of making/ extending/providing the care; the proposed chapter also looks into ways through which care is addressed, assessed and evaluated in order to explore questions like when care works, for whom does it work. Therefore, the task at hand calls for navigating through these stories of everyday lives and analyse what all constitutes care? Ethnography is a detailed account of a long-term first-hand experience with a set of research objectives. If care is to be understood ethnographically it must undergo an analytical deconstruction of the concept where it can be seen as a tacit phenomenon that creates meaning in social relations, relations between animate and inanimate objects, larger institutions of economy, politics, family, religion as well as personhood. The meanings thus created also reflect upon the practical, ethical and emotional dimensions of care. The body of literature available on conceptualisation of care is diverse and is based on the emergent forms of care calibrated ethnographically from disparate locations. The chapter is an attempt to explore the analytical potential of the concept of care by deciphering its association with various factors of a collective life and how these factors impinge upon the actions of recipients and providers of care. Berger and Luckmann (1971) observe that social institutions emerge to provide for stability and direction as in the case of asylums, hospitals and prisons Foucault in his work mentions them the structure of power and executing control. In the field, palliative care at home is seen to break such a stereotypical understanding as we shall see in the discussion. To do so, I am also trying to look into the broader meaning of care which goes beyond what constitutes palliative care. There is an inherent tension between the presumption of theorising care and writing about care unlike other socio-cultural practices. This work speaks of care through its practice. The practices vary from attending to physical symptoms to catering to emotional needs and much more. The practices may be verbal or tacit comprising of holding hand, comforting the shoulder, even a smile or a gesture far more subtle in its expression which raises the question that can writing about care, therefore, be holistic and profoundly explanatory?

Care, in practice, is a process involving multiple negotiations with the factors based on choice, on anticipation or hope, on beliefs, on inequities, and on the collective as well as individual and the relationship between the living and material actors. The precariousness of life of those living with cancer seeks attention to the care practices that are intrinsic to their routine existence. This is required for a few reasons, firstly to document the kind of practices that entail care and secondly to chip in for inadequacies in the extant literature given that the concept of care is not very exhaustively explored in social sciences (sociology and anthropology specifically) (Mol et al. 2010). It is also a reflection of the challenges foreseen while attempting to articulate care which remains a largely non-verbal exercise.[24]How cancer care is carried out post treatment/cure and what are the resulting ramifications? How does the everyday account of the socio-cultural, economic and demographic realities of care providers and receivers create meanings of care? Here I look into the interplay of subjectivities to figure out an anthropological understanding of care as well as explore questions about the ethical and moral aspects of care. Care is usually understood as an act embedded in different social institutions like kinship and family, marriage, economy and polity. Sankar (1991) in early nineties noticed that the anthropological texts missed out on the exploration of the concept of care but the discipline interest changed off late. Also, the western notion of care relies on ideals of

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[24] For more on articulating care, read Mol et al. (2010).

individual choice, rationale and autonomy (Aulino 2012 and Mol et al. 2010). The locally relevant manipulation of palliative care services for those suffering from chronic illnesses results into newer meanings of care. The chapter, therefore, reflects upon the emerging negotiations with the introduction of external interventions to support care at home, a private and personal space and attempts to conceptualise 'care' in this light. The situated reality of care is contingent upon resources and actors as well as decisions about choice and perception. The chapter looks into these interstices to figure out a deeper understanding of care.

The team members and the family largely understand and define care from their own positions. But ill bodies also care for themselves. For instance, in many cases the onus is on the patient to consume medicine, to go to hospital, to undergo a diagnosis, to meet the doctor, to undergo chemotherapy, to undergo radiation therapy etc.[25] In the field, many of the people diagnosed with cancers of different kinds, do it all by themselves often not accompanied by any family member due to financial constraints, time constraints etc. Here, the hospitals are conducting their duty to provide for a treatment but the patient provides him/her a specific set of care. *Anoopchand*, a man in his early sixties attends thirty-six radiation sittings by himself. He stays in as lum area near to a metro station and boards a metro that takes one and a half hour to reach the hospital. Many other people with cancer live through similar experiences. This makes it difficult to address them as only patients as they are their own care providers too. Similarly, the family members providing care are often in need of support as the care work is distressing. They play the

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[25] In Mol (2008), the author referred to patients as consumers/ customers driven by market logic and citizens make their own choices but Mol et al. (2010:9) suggest that even as citizens' patients are never free to choose as they lack option in the first place. For instance, they actively choose to visit their doctors to keep up their health as they have no alternative.

role of providers as well as the receivers. Some of the people in remission for very long periods are strong enough to counsel the newly recruited team members who are struck by gory, loathsome and filthy (“*cancer bohot bhayanak, ghin aur gandgi bhari bimari hai”)* realities of cancer witnessed in the field. One of the nurses, during such visit, was overwhelmed finding ‘young lives’ succumbing to painful deaths and the familial loss of loved ones’. The patient, who eventually passed away, tried to console and counsels her on every visit (four to be precise). This might be an exception, but reflects upon the shifting nature of care receivers and providers. Instead of dwelling into the duality, it thus becomes imperative to acknowledge the ambivalent and ambiguous nature of care.

As stated above, while explicating care, words can be deceptive and insufficient and therefore, it becomes essential to dig deep into the practices, both silent and vocal. Is care a conglomeration of factors responsible for success stories and systemic failures only? To understand the possible slippage of the term ‘care’, I try to analyse the observed everyday interactions by presenting some of the interactions of the team members in their roles as a counsellor, a nurse and, a doctor.

For this chapter, palliative care acts as a lens through which care shall be explored and understood which implies that the study picks up the instances from everyday observation, largely mundane and ordinary, made during the visits with the palliative care services delivery teams. Thus, palliative care provided an entry point to the arena, the households, where the care ‘in a wider context’ is located. The chapter is not in particularly about palliative care but about care in general. While the term ‘palliative’ implies to alleviate the suffering of the dying, this thesis is not only about those who were dying. It is about the survivors, it is about people in remission, about those who have an extremely gradually developing cancer (for as long as sixteen years) where people survive with the help of medicines and the average life span may vary from six to twelve years or far more. Before beginning with any analysis, the study gathers some more instances from the field. These incidents reflect the intervention from varied positions beginning with team members (including interventions on the part of counsellor, nurse and doctor in terminal cases), families and the patient (in order to explicate self-care).

A case of counsellor's intervention

It has been three months since I have been visiting Keshav and his wife. This is my last visit before his death. Keshav is a seventy seven year old retired government officer. His wife is a homemaker and they have two daughters. The family comes from an upper middle class background. One of them is married while the younger one, a successful writer, is in her early forties, single. The parents are troubled by the younger daughter's drinking habit and find her reckless. The team has been visiting him for more than three years when he was first diagnosed with prostate cancer. The cancer was surgically removed and he was leading a 'normal' life. Close to four months ago he suffered from persistent cough and chest pain and on the suggestion of the team he went for tests. Doctors saw a few patches on his lungs. The cancer is back and he has been suggested chemotherapy. He has decided not to go for it as he is aware it's in the last stage and 'he doesn't wish to experience the discomfort of chemotherapy and let nature take its normal course'. As his wife goes to the kitchen, the counsellor, a humble and conversant lady and one of the most experienced employees of the organisation, asks him what has been worrying him. His condition has deteriorated. The team has suggested him to lie down with his head raised using a support of pillows as it will help him breathe comfortably so that he shall be coughing less. The counsellor holds his hand as I see a tear trickle, he confesses that it is difficult for him to leave as he is concerned for his wife.

> “She has never been on her own and I do not trust my daughter. You know it already. My wife does not know how to pay bills or get money from the ATM. I have carried out all the responsibilities for her and now it’s time for her to be alone. How is she going to manage?”

He shares with me that only people he wants to be involved in his care should be the team members from the organisation,

> ‘I am old and it is difficult for me to keep up with hospital visits, your aunty (his wife) is ageing too and she doesn’t have an experience of the life outside the household. I want to spend my time with her and then all of you are there (includes me as well)’.

I tell him that as I am winding-up my work and I may not be able to see him anymore and moreover, it has been the team who has taken care of him over the years I simply come and indulge in conversations. He adds,

> ‘conversations are therapeutic *beta* (a term of addressing someone fondly as ‘child’), they help us forget ‘the sick condition’ and I look forward to meeting everyone including you….it is good to be in touch with young people’.

He further shares,

> ‘The team (addresses the nurse, the counsellor and the doctor by their names) has become a family, (pointing towards the counsellor he addresses her as his real sister) I do not remember sharing this much with the family’.

I see the nurse beginning to realign his pillows, check for pressure sores, lift his legs while asking him if he moves his legs at regular hours, to which he says aunty makes sure he does it. The catheter is in place, the colour of urine looks normal and his blood pressure is fine. In the meanwhile, the counsellor takes up this opportunity to have a chat with his wife who is in the kitchen with the maid. Counsellor gestures me to follow her in the kitchen and there she asks aunty how she feels about uncle's condition. She holds the counsellors hand and expresses,

> 'Sister, even you know he can go anytime, right now he is in immense discomfort' (her lips shiver and she directs the maid to carry on with the work while holding our hands and directing both of us to the dining hall where we sit with her.) I want him to go peacefully. I am prepared. He keeps coughing the entire night, wheezes too and then he sleeps in the daytime. He has no control on his bowels. I remove the diaper at night and he has been soiling the bed. I wash it by myself. I cannot keep the dirty clothes. My daughter and I lift him, this hurts my arms and I am old too. But more than me he is in discomfort. Gasps for breath often, then I put the oxygen mask on his nose. God should make it easy for him now, have you seen the new sore beneath his ankle? It has developed recently.' (Wipes her face with the kitchen towel)

The counsellor asks if she has talked about it to him. Has she tried to assure him that he can go now? The wife looks puzzled while the counsellor holds her hand and says,

> 'He needs to hear it from you. He is suffering but fears how you will manage your life especially doing basic errands like paying cheques as he has taken care of everything till now. You talk to him. (Pauses for a moment and looks at me) we

> have seen patients hold on to life this way. They await permission and assurance."[all this while the old lady is seen wiping tears off her wrinkled face, rubbing her nose and joining her hands in prayer position mumbling, God please release him off his suffering. (*"ishwar mukti do takleef, se mukti do"*)].

Afterwards we leave, and Keshav ji calls the counsellor after four days at wee hours in the night. Counsellor shares the conversation with us on the next morning, saying 'Pooja, do you know Keshav ji passed away? Before I can say anything, she adds,

> 'Last night he asked his wife to call me at around half past two and spoke to me saying he may not be able to see us anymore but we must keep visiting his wife when he has left. I asked him to sleep and assured him that we would be visiting them today and he must not worry about aunty. At around half past six, his daughter called us informing he passed away peacefully with aunty by his bedside.'

A case of nurse's intervention

Sumanta in her late sixties suffers from advanced pancreatic cancer. She belongs to a middle class business family. Her debilitating condition is a cause of concern and distress for the family. On our visit her daughter-in-law, shares that the family called for Sumanta's daughter, Madhu, as her kids are on a summer vacation and she can spare time for her mother. Now a days, daughter-in-law's main concern is 'not cancer, neither death' but the painful cries of Sumanta who suffers from severe constipation as a side effect of medicines and extremely low consumption of liquids and fibrous diet. She believes death is universal and has to come one day but detests a 'life of agony and dependency'. Madhu can be assertive with the patient given her relationship unlike the daughter-in-law who is scared to intervene beyond a point as she does not 'wish to take any blame of laxity or force feeding on her in the final days of her mother-in-law'. The nurse comes to know that it has been four days since the patient has been unable to pass the stool, two days ago when she passed some stool her rectum bled. They wanted to take her to a hospital but she 'doesn't want to leave the house as she fears dying outside the home'. The family wants to keep up with her wishes. She has been waiting for the team since morning, had it not been a Saturday and a Sunday her wait would not have been so long. While I am standing with the team, the nurse takes out hand gloves in order to perform a digital evacuation of the bowels; Sumanta begins to sob and holds her daughter's scarf. Madhu explains that her mother is extremely shy and has never undressed in front of her own daughters or sisters too. She won't untie her lowers at all, the counsellor convinces her about this 'routine procedure' and she starts wailing and speaking hesitantly that her cancer is not killing her instead making her die of shame ("*cancer nahi maar raha sharmindagi (shame) maar rahi hai"*). For almost half an hour the team sits there talking to her in the hope of convincing her, in the meanwhile Madhu interrupts suggesting that they might be getting late and she should get it done, 'after all, all of us are woman here'. I suggest of going out so that there are lesser people to intervene her privacy and make her feel comfortable. The team asks me to stand saying that they might need some help with supplies as her head lies buried in the counsellor's lap. Finally, Sumanta gives in to the coaxing, while I put some lubricant in the hands of the nurse who helps Sumanta defecate using digital evacuation. The procedure lasts for ten minutes often interrupted by Sumanta's feeble cries. The entire room smells of faecal matter and the daughter as well as daughter-in-law wraps their faces with the help of stoles. They switch off the fan and switch on the air conditioning. Madhu calls her brother to get an air-freshener. The team suggests them not to get anxious and decides to leave. When we leave, Sumanta is in tears while trying to cover her face with a stole. She joins hands for a 'thank you' and we hug her. She asks the nurse why do you do such work to which the nurse replies that it's for her relief. She shares with the nurse that while her own children covered their faces due to the fetid odour, rest of us did not and finds the act 'Godly'.

A case of doctor's intervention

Similarly, Rajesh aged forty five with his left cheek totally disappeared due to oral cancer awaits the arrival of team desperately. When we enter his room with dilapidated walls and no window, space small enough to occupy a cot, a chair and a fridge with a television hanging up in one of the corners, clothes strewn here and there and a whiff of foul air, I see him reduced to bones and squeezing himself on to the bed in utter discomfort. His wife is washing utensils outside the door when the doctor asks her about his well-being. Callously she informs us that he is lying inside and keeps stinking ('*pada hua hai ander…bass ati hai is se'*). His mouth is covered with a clean white cloth; I am accompanying the counsellor and the doctor this time. The doctor removes the cloth as Rajesh sits with the support of the wall. His tongue falls out and the jaws can be clearly seen with no flesh of the cheek to cover it and a small hole visible on his neck. The counsellor is a new recruit and it's my very first day in the field after the pilot work. She tries to cover her face and exclaims in pity as well as horror. Doctor asks her if she is ok and later asks me too, in the mean while Rajesh is staring at all of us. He keeps shaking his head vigorously and very frequently, the doctor takes a torch and tries to see the insides of his mouth as well as the hole in his neck and finds it infected with maggots. The wife leaves her work in the middle, stands up and sobs while saying he has never done anything to deserve this. Counsellor, holds her by her shoulders while the doctor asks for turpentine oil. Taking out a dropper from the bag of medical supplies, he fills it with the oil and asks Rajesh to lie down instructing him not to swallow the oil but to spit it every time he gets to taste it. As soon as the oil seeps in, the maggots' surface on the inside corners of the wound, some falling off his wound and wiggling swiftly on the bed. The doctor wearing hand gloves begins to pick them up and asks me to hold a bowl of water in my hand and count for the maggots which he shall be dropping in the bowl. The counsellor is ready to hold the bowl but later the doctor confesses he could see stress on her face while he found me 'strong'. We count a total of forty four maggots. Wife is scared and asks if he should be allowed to sleep in with the family? She is informed that maggots are not related to karma or disease but to hygiene. Since both of us, the counsellor and I, are new comers the doctor is asking us questions about a lot of things we are observing in the field. He asks everyone in the house including us that what are these maggots and where do they come from? No one knows, he makes it sound like a viva voce and asks me to 'attempt the answer'. I am a little hesitant because of the entire process and answer that these are housefly larvae the open tumour attracts houseflies. While he declares it the 'right answer', Rajesh keeps staring at us, shaking his head often. The doctor reminds then that the team had instructed the family to cover the wound to avoid flies but it was difficult in the kind of place where they are living in. Rajesh begins to cry and covers his face with his hands; the doctor consoles him and asks him to write his thoughts as he cannot speak anymore because of partially losing his mouth. He writes his desire to die and relief from the suffering (‘*mukti chahiye*’). As he joins his hands in a gesture to thank the doctor, tears well up in his eyes, the doctor holds him, smiles and suggests the family to take him to the hospice, for he is unable to receive proper care at home. He again writes on a paper, ‘take me anywhere I am awaiting a peaceful departure (‘*kahi bhi le jaoshanti se jana chahta hu’*) as we move out of the house, the doctor says this can be their last visit and after a fortnight we come to know from the family that he took his last breath in the hospice and he was at peace. While such a demand was counselled in the light of ‘sanctity of life’, later such cases were discussed with much sympathy expressing desirability for an early death. I often came across narratives like, ‘*ab chale jana chahiye*’ (now (he/she) should go); ‘*bas mukti mil jaaye bechari ko’* (poor thing may attain mukti now); ‘*dekhi nahi jaati uski halat ab bhagwaan bula le use apne paas'* (it is difficult to see him in this condition, God should call him). Byock (2000:47) reflects upon the hesitation on the part of the team members when patient make such demands and it is difficult for them to comply. In the field, such reactions often reflected the inability of the teams to cope up with the suffering despite their earnest efforts and the resultant being ‘burdened with suffering’ (as shared by some of the caregivers).

The above incidents reflect upon the interventions by the team members (counsellor, nurse and doctor respectively) in their respective capacities in a home based setting to bring relief to the patient. Though explained using individual cases, the approach of intervention largely remains similar despite varying patient circumstances. From the teams’perspective, one can observe the dissimilarities based on economic status and educational background. For instance, a few team membersshare their experiences with upper class households especially the kind where the patient is provided with nurses and servants but the family is not regularly around. A few counsellors share interactions with family members from such households. As per them, instead of the team, such families desire the services of counsellors only. Also, as in one case, the family wanted to know the qualifications of the counsellor. The counsellor shares that it is only recently that the organisation has started recruiting people with specialised educational backgrounds otherwise one needs to be a graduate to undergo a counsellor training based on interview selections. Similarly, the team members share their scepticism with educated families who have a biomedical understanding (by which the teams imply to a negative perception) of palliative care, in such cases the teams keep a limited involvement only with the patient and try to ‘only give medicine, check the pulse and allow the nurse and doctor to intervene *(“bas dawa de di or navaz jaanch li, matlab doctor aur nurse ko aage kar diya”)*. Empathy is always a desired characteristic along with good communication skills. Also, while talking to the counsellors, most of them have some sort of previous experience as field based health workers associated with non-governmental organisations. As shares one of the counsellors,

> educated people are aware of this term ‘counsellor’ and therefore, they have really high hopes from us….sort of expertise they would presume from a clinical psychiatrist. We do not get to work in clinical settings, have no sense of privacy as the family is usually around, which makes our work more of a social worker who provides information but is not professionally well equipped with the lore of counselling. As for less educated people, we are the doctors who do talking. (*‘padhe likhe log ko hi pata hai counsellor kya hota hai isliye unki umeed bhi zyada hoti hai, unhe lagta hai hum doctor/psychiatrist wagera hain. Ab hum*

> *clinic main toh kaam karte nahi, jahan patient ko akele main time de yaahan sara kunba hota hai, privacy toh bhool jao. Hum toh bas social worker bankar reh jate hai. Jo kam padhe likhe hai unke liye hum baat karne waale doctor hai.*)

It is observed that the counselling staff performs under immense pressure. Multiple reactions on the qualification vis-à-vis 'clinical expertise' were often heard from within the group as well as from the doctors and the nurses. Often heard statement would be, 'what do they other than chit chatting' ("*kya karte hain, gappein marke aa jaate hain*")? While the reaction comes from a platform which lays more emphasis on interventions to the bodily discomfort, the psycho-social aspects are often labelled as 'banter'. There are no outright rejections, instead indulging in frivolous mocking like, 'someone should pay us as well only for talking' (*"bhai koi hume bhi paise de de gappein marne ke"*). The counsellors often make a strong point in their defence but leg pulling is common on these grounds. From within, some more 'academically and professionally aware' counsellors find the entire process of incorporation of counsellors in a team as a gap-filling mechanism as one shares that,

> 'Doctors cannot be hired in large numbers for the reasons linked to remunerations and for nurses, most of them, are not interested neither well trained in counselling. Counsellors are cheap labour.'

In the field, many of the counsellors and nurses are found to have developed a deeper association with the families and the patients. Some of the effective counsellors have no academic background in counselling but a long experience in the field and the art of being perceptive, empathetic and attentive listeners helped. The situation shared above, therefore, reflects attitudes and practices that seek professional validation through knowledge grounded in disciplinary boundaries. With new trainees joining the organisation, a degree in psychology was a desirable trait and such candidates were more confident from the onset of their training too. I had an opportunity to interact with one such candidate, while training with one of the teams, the trainee struck a conversation with me.

> ‘So do you like it?’ (I looked at her not very sure to understand what she exactly meant by that question.) ‘Going to people’s houses I mean, some of them are located in slum areas and unauthorised colonies. Dingy and smelly places, you don’t mind it? (I smiled and nodded in negation as she began to speak in a matter-of-fact fashion) ‘I cannot drink water from every home and the worst part is to have your lunch on the roadside, everyday inside the car. This is only for training that I am here, I am told that I will be placed in a new team at a “much better location”.

Similarly, the nurses forged manipulations in order to provide relief in the end days while negotiating the knowledge barriers extant in doctor-patient understanding of what provides comfort. The nurses also act as the bridge between two different levels of understanding, the doctor and the patient or expertise and experience. The idea of the ‘suitability’ of care instead of understanding the moral code of care is acknowledged and negotiated. For instance, the observations where nurses (as a practitioner of care as per the biomedical understanding, other than the doctors) render support to the patient’s choice of comfort while trying to negotiate their own professional training and the lay understanding of comfort. Similarly, the nurses visiting the houses of patients try to extend means of care by accepting and assisting with the regular household items instead of specialised medical equipments given the resource constraints on the part of the organisation and the insufficient financial means of the families. The practicality of some of the materials used can be questioned in the medical practice but these artefacts are reflective of the attempts made in establishing relationships to enable care. Often a rolled up quilt, an old tyre, honey dressing, and water boiled with some pinch of salt are replacements for the adjustable beds, air mattress, inflatable ring cushion, and normal saline. The idea is to make ends meet and yet sustain the trust in care. These ideas are not always proposed by the nurses and in many cases, families or the patient present a comforting alternative which may sound 'foolish or too lay' for the doctors yet nurses are open to accommodate it. One such family shared their experience with the team's doctor who scolds them often and found it easier to communicate it with the nurse. The local understanding of care on the part of the nurses defy the hierarchies of knowledge established through the means of training and interactions with doctors further leading to newer constructions of nursing care. The patient and the families often lament the difference between the doctors in the team and the doctors in the hospitals. As Anita shared, I am scared of the doctor (from the team) but the hospital doctor is worse' (*"doctor se darr lagta hai par hospital ki doctor zyada kharab hai."*).

In the field, some of the doctors in the organisation are perceived better than nurses and counsellors too. Similarly, male patients are found to be more comfortable with the male staff (either the doctor or the counsellor) as during a visit with the all-female staff, male patients often inquire about them. Relatively less female patients are found to share such preferences. Therefore, the distinctions between good or bad doctors/nurses/counsellors are highly contextual. As a young female patient discussed the intimacy concerns with an elderly male doctor, she shared her happiness on our next visit about the whole experience. On the other hand the same doctor tried to comfort a middle aged woman who had recently undergone double mastectomy and the woman took offence of him patting her shoulder. The difference between age, gender, cultural understanding of touch were discussed in the next meeting. Such misunderstandings emerged in the field and the organisation intervened tactfully. There were cases where the organisation fired employees due to their rude behaviour in the field irrespective of gender and age.

Human beings have their own propensities for working in particular locations as well as in particular fields. The economic incentives, work surroundings and other features like holidays and office timings often become reasons for people to join an organisation. The lack of empathy in a field like palliative care is liable to produce poor care. The above narrative reflects abhorrence to the site of intervention but interest in counselling has been professionally and academically determined in the narrator's case. The attitude may have its bearing upon establishing bonds as discussed in the earlier chapter. Still, the everyday interactions between the families affected by cancer and the team membersfrom the organisation shall continue as per the demands of the profession. I will speak about the nurses' perception later in the chapter.

Also, despite the personal idiosyncrasies, care is largely regulated through incentives in any professional setup. Paid care therefore, may differ from unpaid care primarily on the basis of the features reflected above. And as Kleinman (2008:22) shares from his personal experience of caring for his wife,

> "Caregiving is about skilled nursing, competent social work, rehabilitation efforts of physical and occupational therapists, and the hard physical work of home

> health-care aides. Yet, for all the efforts of the helping professions, caregiving is for the most part the preserve of families and intimate friends and of the afflicted person herself or himself.”

Care and the role of family

The palliative care teams are seen to judge the families on the basis of the binaries of good and bad care hold relevance here. This section draws from Mol’s (2008) description that good care has little to do with the patient choice and therefore, creating more avenues for the patient (or care receivers) to choose from is futile. She perceives care as a process where the care-giver keeps trying without being driven by the market logic and hence, in a supposedly resource poor country like India care appears a more plausible choice in comparison of seeking cure especially in the case of those diagnosed with advanced cancers[26]. She concludes that good care is not a matter of making well-argued individual choices but is something that grows out of collaborative and continuing attempts to attune knowledge and technologies to diseased bodies and complex lives. In a later work, Mol et al.(2010:7) state the good and bad care are not always obvious, sometimes good intentions lead to bad care too.

In the field and later from the extant literature within sociology, anthropology and clinical studies [Clark 1993, Fine 2005, Joad et al. 2011] care is understood as either good or bad. But before arriving at the judgment it becomes imperative to have a relative understanding of caregiving as a practice. Care is often seen as a moral import laden with judgments. An analysis of this sort presents care in a positive as well as a negative light.

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[26] Read Rajagopala and Venkateswaran 2003 for a detailed picture of palliative care provided to cancer patients in India.

Jitesh Yadav, a paraplegic in his mid-forties, stays in the confines of bricked walls which could not be plastered due to lack of money, awaits his moment of release every day for almost two years now (2013). He expresses his discontentment with organisation's efforts as well as his wife's 'recklessness'. As per him, the organisation must provide him more assistance in terms of rehabilitation (he has been provided with a sewing machine on his demand but now he feels he should have asked for something else.) He is provided with a rippled air mattress but it was punctured when his daughter tried to wash it. When his wife tried to put him in the wheel chair with the assistance of his children as they were to visit the hospital for a regular follow up, the mattress was smeared with urine. The daughter shares that the urinary catheter had come out as he would regularly try to scratch his groin. The nurse doesn't believe in her explanation but nevertheless believes that they tried to clean the mattress and in the process it was punctured. He wants another one. But the organisation receives its supplies through charity and cannot provide it to him immediately (takes them two weeks and a warning not to puncture it again). Sometimes, he has to buy medicine for himself and it is extremely difficult provided his financial condition. He complains that his wife intentionally hurts him while bathing him. His sores are often hurt during the act. The wife, on the contrary, admits dropping his legs on the bed sometime unintentionally as his body is limp and heavy and giving him bath all by herself is a tiring task, she complains that her own joints pain.

His caregiver, his wife, 'wishes for his hands to have been crippled too, the only movable thing in his lifeless body other than his acerbic and abusive tongue'for she and the neighbours around, who have come to her rescue many a times, also share how he abuses his wife and uses his hands to pull her hair, dig his nails in her face, as and when she comes near him to tilt his head, adjust his pillow, shave him, sponge his body, empty the urine bag and dress his deep crater-like[27] bed sores one of which used to expose the bone as well.Jitesh keeps mentioning the woman ('who wore pants like I do') whom he was in love while fathering four children with his wife. His wife, Rama, perceives his disease as his only way for penance and 'curses' him for a longer crippled life. She perceives his disease as is his punishment and not a disease, a punishment for the betrayal of the wedding vows as well as his male ego which he brandished when he could earn. She admits that he never misses a chance to physically hurt her as he hates being dependent on me; it is his guilt that he is frustrated about as he is no more capable of taking care of his basic bodily functions like passing stool. As we come out of the house and she walks along with us to collect his medical supplies she angrily shares,

> 'When I had gone out he was lying in his own soil. He cannot feel it but can he block his nose? God is seeking my vengeance. What about me? I shall be caring for him till his last breath so that he dies of guilt, shame and what all he has done to me. He will not die soon, he has to live more (for penance).' *("Apni matti main san rakha thaa jab main bahar gayi thi. Pata toh nahi chalta par badbu toh aayegi, naak kaise band karega? Mera badla bhagwaan le raha hai, mera kya hai ..main sewa karungi jab tak hai thud marega pachtawe se, sharam se aur jaisa kiya hai mere saath. Jaldi nahi marega yeh, ache karam kiye hote toh na, abhi isne or jeena hai."*

She works as a tyre-beed peeler to extract clean steel wires from the used vehicle tyres', her hands are punctured and scathed in the process. Extracting a kilo provides her two

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[27] This is a sign of poor care, the team kept telling the family and tried to teach them easy ways of dressing the wound for instance by doing honey dressings which apparently have been very effective in very many cases.

hundred Indian rupees and the process takes close to three to four hours. Sitting in neck bending position has led to cervical spondylitis. She has been ignoring her pain for the fear of leaving her husband unattended. Her elder daughter is sixteen and she has been trying to seek an alliance for her. A boy's family visited their house but seeing Jitesh's bed-ridden state they refused the alliance citing his 'cancer' to create problems for his daughter or the children she might bear.

In the above case, the patient is discontent with the care he receives. The team is of the opinion that he is a demanding patient. The wife performs all acts of 'care' but keeps reminding him of his unfaithful past and his violent and abusive nature. This instance is to bring up the shady nature of good or bad care. The family discord reflects multiple meanings attributed to care. When we visit her after his death (almost two years since we first met), she wails as she hugs the nurse. While wailing she keeps singing a song, as she walks with us to drop us till our vehicle she mourns his sad and slow death and how she kept asking him if he wanted to meet the other woman but he didn't say much. She wanted to know her address so she can trace this woman but he kept quiet. She mourns her loss as a widow but doesn't sing this time instead expresses the relatives from her husbands' family are willing to give his share in the ancestral property to her. Later, I ask the nurse if she is aware of the reason behind her singing as a part of mourning to which the nurse adds at her house she was surrounded by her relatives and singing as a way of expressing sorrow reflected that she cared for her late husband and reflects sadly, 'in a way she was the only one who cared for him' *("ek tarah se khayal toh wahi rakhti thi").*

So as to seek an understanding into the care practices of the family, one needs to look into multiple aspects of their lives for instance gender of the caregiver, economic condition of the household, relationship of the care giver with the patient, personal health and much more. While the teams are abound with professional responsibilities, the personal sphere is relatively complex as it requires caring for the self as well as the other while struggling with emotions like love, loss and fear due to an intimate engagement.

> “We struggle with family and close friends to find practical assistance with the activities of daily living, financial aid, legal and religious advice, emotional support, meaning-making and remaking, and moral solidarity. About these caregiving activities, we know surprisingly little, other than that they come to define the quality of living for millions of sufferers.” (Kleinman, 2008: 22)

While unable to eat, the patients have to consume a lot of medicines and some of them including morphine lead to constipation, one of the major problems faced by the patients. Constipation often adds to psychological discomforts of the patient due to manual digital evacuation of rectum, using procedures like enema and making use of suppositories. In the field, constipation is a regular ordeal and patients often hurt themselves due to over-straining leading to injured rectum. Even when the teams would be taking referrals for patent visits every morning, many families would call the teams’ members who would rush to assist the nearby patients before leaving for the field. In my presence, I observed, the patients, often wept inconsolably. As Krishna aunty, as we used to address her, shared, ‘I never imagined I will live to see this day. It brings shame even if it is a regular task for you (told the nurse)’. In one of our visit, the elderly woman was lying on the floor of the house. Her daughter-in-law was trying to make her drink lemon water while she was constantly refusing it. On the insistence of the counsellor, she took two sips from the glass and hugged him while wailing. The team stared at the daughter-in-law who shared that she had been in a lot of distress due to constipation for the last four days. Today, the daughter-in-law decided to perform it manually as she had observed the team doing it. The patient, though shy and reluctant, gave in due to utter discomfort was unable to overcome the experience.

In addition to hunger and bowel discomforts, patients often share their discomfort or displeasure, rather, with the urinary catheter. In certain cases, families insist on adult diapers which are known to cause pressure sores in the case of bed ridden patients. Sometimes, despite the warnings, the families and patients insist on adult diapers. The sight of bag filled with urine is often mentioned to create a sense of uneasiness, 'what will people say'? Despite the discomfort, patients share their sense of relief and escaping shame from incontinence. In many cases, it was observed that people were initially reluctant towards insertion of visible tubes and bags. Ryle's tube meant to feed people who are unable to swallow is often abhorred till the moment that the tumour grows large enough to make swallowing a difficult task.

In case of Pawan, in his mid-forties, with throat cancer, he and his wife were reluctant to get a Ryle's tube inserted. 'These tubes do not look good. All those who do not know his disease status will get a hint too. Till the time he can swallow, no matter how little, we will stay away from tubes.' In his last days, he desired for it but the wife refused insisting that the doctor in their neighbourhood was able to put him on glucose drip. A few weeks before his death, he used to lie at the door of his house, in a crouched position unable to sit, and was not allowed to crawl around inside the house. Every time he wished to spit, he crawled outside on the dust laden streets and spitted nearby drain. Whenever, we used to reach he would demand for mango juice from the stacks inside the refrigerator, as the wife used to run a small shop from the house. When we came to know that he had been unable to eat anything for the last two days and was on glucose drip (on the same morning, he pulled out the needle and refused for anymore drip provisions) we asked his wife to give him lemon water or whatever he desires for. He insisted for a frooti (a packaged mango drink) to which she replied, ‘drink water with sugar and salt as there are no lemons. ‘By selling frooti I will get some money, he is anyway going to pass soon. Lemons are cheap as if. (*Frooti bechke kuch toh paisa milega isse toh aise bhi jana hi hai, nimbu kaunse saste ho rahe hain*?)’. While the wife might be facing financial constraints, this bony man with only a cloth wrapped around his waist was visibly weak, hungry and in a lot of pain. The counsellor, was a little irritated with the wife’s behaviour, but requested her to take him in the afternoon OPD at a hospital so that they could intubate him. He died after two weeks. The neighbouring doctor shared that he wasn’t fed with any tube; his arms had been punctured multiple times in order to find a vein for injecting the glucose using a drip. His sixteen year old daughter shared that he took so much time to die despite being hungry. In this case, the abhorrence for tube was not related to stigma or shame but to family discord and indifference towards the patient.

These sufferers can be us and it is only a matter of time and chance. In such a case, an exploration into the world of home care brings us closer to the perceptions, beliefs, preparations and practices that hold relevance to each of us. On the other hand, Jitesh’s case demonstrates a complex understanding of perceptions towards good and bad care. The teams, in many cases, used the instance of abuse as cases of bad care. For instance, a patient who stayed in a makeshift room on a terrace without any fan suffered from oral cancer and used to communicate through his diary. He stayed with his sister and her husband who kept him outside the house for his wound was horrific to look at and smelled bad. He often wrote in his diary how he was beaten using slippers by both of them, wasn't fed properly and regularly. The team expressed pity at his plight and referred to it as bad care. I found it ironical to use the term 'care' at all in such cases.

Self Care

Many of the survivors observe a change in attitude and a desire to pursue a healthy lifestyle post illness which reminds me of Foucault (Ecks 2004:82),

> "Care through food, exercise, yoga, and change of lifestyle are a part of traditional corpus of knowledge. Foucault in his work on technologies of self-care refers to it as ancient medicine with reference to Greco-roman practices. Foucault argues that the ancient Greco-roman medicine was not to exercise control as is the case of modern medicine (the birth of the clinic). Thus, medicine was not conceived simply as a technique of intervention, relying, in cases of illness, on remedies and operations. It was also supposed to define, in the form of a corpus of knowledge and rules, a way of living, a reflective mode of relation to oneself, to one's body, to food, to wakefulness and sleep, to the various activities, and to the environment. Medicine was expected to propose, in the form of regimen, a voluntary and rational structure of conduct. (Foucault 1986, pp. 99–100)"

Vibha is a middle aged woman full of life and active with her spiritual engagements. Her belief in her spiritual 'guru' provides her a lot of positivity (*"bindaaspan")*. She calls her cancer an accident (*"durghatna")* which can happen to anyone. She is happy to have come out safe and credits her positive attitude and acts of charity. In addition, she shares that she is very watchful of her arm[28] after the mastectomy does regular exercises. She shares that she washes her clothes with her hands so that it functions more. It is swollen but she does not face any problems because of the oedema. She says that while she ate healthy food especially lots of fruits, nuts and vegetables after her treatment, she also began to walk a lot. She believes in taking care of her looks and likes to wear jewellery and vibrant lip colours as it makes her feel that she is not a patient(*“mareez”*).

In the case of Mrs. Bhisham, she is a woman of fewer words. After her mastectomy, initially she was not hopeful of surviving. Her husband passed away in an army combat. She takes pride in being a wife and a daughter-in-law of commissioned officers. Her son was young at the time of her diagnosis and she was determined to live for her son. She perceives the life after her surgery as a second chance and keenly observes healthy lifestyle by consuming organic food: pulses, grains, vegetables and fruits, yoga, reikei, zen meditation as well as reading inspirational writings. She believes light music, dim lights and calm surroundings have helped her be in touch with her inner self. She shares that she has become more positive in her outlook than her younger self. Earlier she was always looking for perfection. As a member to a family with army background, she still believes in a disciplined life but has ‘given up of worrying for petty matters like matching cushions and worrying over broken cutlery’. Moreover, she believes in living “here and now”, the Buddhist philosophy.

Lalit in his early forties, who stitches clothes in a boutique and commutes using a bicycle and has cancer in his right hip, shares,

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[28] When mastectomy is performed usually the lymphatic nodes are also removed along with the breast as a result of which lymph begins to accumulate in the arm of the same side causing oedema. Patients are asked to exercise the arm throughout the life to manage the oedema.

> ‘Doctor’s advised me to cut my leg and I asked if that would assure that cancer would never appear again. They were not too sure and I decided to keep my leg. My son is of fifteen pursuing his studies and I was diagnosed with cancer a year before he was born. My life is as normal as yours. The only difference is the fact that sixteen years ago I was made aware of a malfunction in my body. It has not caused any problem till now. I take care of my medicines; keep a check on my diet and nothing much. I am not a patient, doctors may see me that ways, but I am not neither bed ridden nor dying. I go for regular six monthly check-ups and I have heard normal people in America also do that…all those who do not have cancer for example (people) like you (smiled and directed his hand towards me).’

He further shares that life is precarious and the railway track behind his house reminds him of this fact. Two days ago, bodies of two children were found in two halves while one of his clients lost her husband to dengue. He therefore feels, each body needs to be cared by regulating “healthy diets, exercise, good sleep and avoiding stress (which may not always be possible as he adds)”. He makes sure to have jaggery and groundnut in the winters along with vegetable soups. For him, care is in the food. A little concerned over the water supply to his home located in an unauthorised colony, he feels, one cannot take all precautions but try their best. This reminds of the logic of care where Mol (2008) discusses care as unattractive. She suggests that patients cannot buy care as a product of consumption even if they desire to as one needs to actively engage with care ‘painfully, enduringly’ and as one of ‘prominent’ members of the team and not a mere passive recipient. Many survivors share their changed lifestyle, which now includes yoga, pursuing vegetarianism and washing vegetables for long to make them pesticide free.

Men and women belonging to different economic strata, have similar notions. Notions regarding being positive in life, pursuing healthy life style, being more in touch with their inner-selves. These notions were actively pursued. Self-care is active and indulgent.

In patients, undergoing a difficult prognosis, the sense of care for self is often shared. It is to fight against dependency. People like RajKumar and Mrs. Bhisham often share their discontent with everyday reliance on technology. Both of them talk about their routine much similarly where they have taken up walking to long distances. Similarly, they share that they have replaced cold drinks with butter milk, home-made fruit juices, shakes and drinks using raw mango, mint, ginger, sugar, salt, coriander, lemon etc. Mrs. Bhisham insists on serving any particular drink on every visit. For her, lemon water is a good way to flush out toxic. The other households are also known to rely on such products too but Raj Karan and Mrs. Bhisham talk a lot (on every visit) about incorporating such changes strictly into the household.

Care, therefore, represents itself through multiple ways; through consumption of food, making bed, tending to physical symptoms, cleaning, washing and bathing, or even spending time with the patient over conversations. But care also implied working for the family, leaving the patient alone to go for work or the patient herself going to work in order to earn to get food for her children. Two such women, Jinni and Sushma, worked as domestic maids in the neighbouring kothis (bungalows). Jinni is a Nepalese women with two young children (three and five) who suffers from CML and is consuming Imatinib (a drug with a mean survival rate of five to eight years) which she obtains free of cost from the hospital. Her husband is an alcoholic and cleans cars to earn for his alcohol. She works as a domestic maid in different houses and takes leave for her hospital visits by citing stomach ache. She earns around 2000 rupees per month and uses the money for food for her children and sometimes ‘a’ fruit for herself. Sushma died within three months of her diagnosis and treatment, her husband stays at home citing some vague illness while she used to work in the households as a domestic maid even during her chemotherapy.

In case of many patients, there is an initial hesitation towards the caregivers’ assistance for toileting needs. This hesitation is often met with inconsolable sobbing and a sense of ‘being a burden on their loved ones’, ‘of no use to the family’. An assistance involving others for the toileting needs brings a sense of loss of privacy. Over a period, however, patients get comfortable and seek the help of a family member or for the nurse visiting them. An early morning phone call in the centre office, for seeking assistance in toileting needs was very commonly observed. Many caregivers in the family downplay the issue but sometimes share the initial awkwardness by saying, ‘what to say, one has to do it’ *(“ab kya karein, karna padta hai”).* The caregivers share their woes with lifting and transferring the patient as well as cleaning the mess and doing the laundry. In many cases, the caregivers are elderly men and women themselves. They complain about the physical labour that goes into such tasks. Also, as a husband whose wife is in remission for eight years now shares that both of them are above seventy and after her surgery for some time he had to make her walk to the toilet as she could not balance herself. He shares,

> ‘I am old, she is too but then we need to support each other. If she falls I will have to take care of her that’s why all through the nights I would get up and walk her to the washroom. Madam would not agree to pee in that utensil (bed pan) on the bed.

> So have to do it'. *("main bhi boodha yeh bhi boodhi, par support karna padta hai. Gir jayegi toh mujhe hi karna padega isliye raat raat main uthkar bathroom le jata tha, madam maanti nahi thi woh bartan main karne ko, bed par. Toh karna padta hai.")*

It must, however, be kept in mind that the categories for the positives and negative feelings are never in isolation with each other, they don't emerge in binary instead, the attitude of the family members is contingent upon the daily situations. The notion of being useful to the loved one is shared by many of the respondents and often people speak of doing good karma on their part. But a large number of people in the family see care related activities as emerging out of necessity and no other alternative. For instance, Piyali's husband once shared,

> 'I will not throw her..you don't do it with your own people. I am tired taking care of her and my funds have exhausted but I have the satisfaction that I did everything in my reach. And then I have to answer him as well (pointing his finger towards the deity of lord Shiva)'.

As questioned Kavita's husband, 'will you throw your family member away? Even if I am sick or sleepy, I realise she depends on me completely. It is difficult but that's what you have to do.'

Many families accept that meeting other care givers gives them strength. The task of care giving prepares them for future situations of crisis as well as lends them patience, and helps with self-control over emotions like anger, grief and be grateful [when people anticipate that the situation could have been worse ("*'isse bhi bura ho sakta tha*")]and live for the moment. They understand it as a matter of living the life through these situations.

Once at the house of A, we found out that his usually jovial wife and daughter are ignoring him through little gestures which they otherwise do regularly. They appear a little restrictive while talking to us. During the course of conversation, the team members probe that something is wrong. The patient begins to sob and the team is assured of some discord within the family, they begin to empathise with patient presuming his position to be the most vulnerable and ask if someone in the family hurt him, verbally or physically. He stays quiet and keeps crying. Ultimately, the wife breaks down as well complaining about her husband's alcohol addiction. Unable to swallow anything from the mouth due to a large cancerous growth inside, he has been intubated. Every morning after breakfast he visits the local park during the winters and off lately, the family has found out that he returns home drunk. The wife complains that all her efforts are in vain. Her daughter comes out of the kitchen, visibly distraught and cries. The mother shares that both of them are caring for him desperately. They give him everything on time, be it meals, a bath or massage. They do not sleep on the upper floor considering his needs and spread a mat on the floor to sleep near his bed. She shares that she is unable to sleep worrying about him, she has stopped visiting the temple or meeting her friends now as her key concern is to care for him but he pays no heed to their actions. Many of the caregivers, for instance A's wife and daughter, shared during one such conversation that relatives and neighbours often suggest them on how to care for A, 'multiple ways of dressing the ruptured oral tumour, ideas to hide the feeding tube, providing new kerchiefs every day and preparing mutton curry for A despite the financial constraints (per kg mutton costs

400 INR and his wife often sobs while expressing her inability to feed him regularly). His inability to taste it is a secondary notion and is barely considered by the visitors ‘close’ to him, the relevance of mutton curry was associated with more nutrition in comparison to other kinds of food as well as A’s fondness for the non-vegetarian curry. His daughter, S, laughs off these ‘pretentious concerns’ during our visits sharing that ‘those who won’t get him a glass of water have umpteen suggestions to make and (we) who are doing everything have no choice but to listen and let it be, only the doer knows it’.

An alternate understanding of care

The care observed in field must not always be understood as alleviating the suffering caused due to cancer. Each team visits a few survivors too. Most of such families have an association with the organisation for a couple of years. The survivors are cancer free for much longer periods too and later came to know about the organisation. The teams visit them over the years while they have the alternative to choose for no more visits. As one of the survivors’ shares, ‘now they come for chit-chat and I want them to come’. They were with me during my difficult times and we have developed a relationship now; not only with me and my immediate family but the extended family too’. A usual visit to a survivor’s house means meeting the families over tea and snacks, light hearted conversations. The conversations range from someone’s marriage in the family to a new born; including the family feuds, disputes and intimate associations. Some of the members find it ‘ridiculous’, ‘unprofessional’ and ‘a wastage of time’, more like ‘discussions over kitchen-politics’. But families and survivors eagerly await the team visits and share that talking to those who cared and supported them when it was much needed is still therapeutic as they are neither judgemental nor ‘charge any fee’. For instance, Seema regularly instructs her son not to finish all the ice creams before the first Monday of the month as we used to visit her, her husband works in a catering supply chain and she would ask him to get ice-creams whenever the team visit is due. In case of patients, other than the survivors, one finds a similar sense of hospitality. Care is understood as *sewa* for the reason that the organisation doesn’t charge for any of its services and people often wish to express their gratitude. The teams do not relent easily to such exchanges as it goes against the organisation’s protocol and some members find it embarrassing too. But so many families do not take ‘no’ for an answer. Kamala’s husband cooks vegetables or make pickles and waits for us to taste the sample. Similarly, Minakshi Jain’s husband would ask us to come in the morning and in case the team is unable to come early he saves a few extra servings of the breakfast he made. Deepa instructs the teams on phone to arrive at home after finishing all the visits when she wishes to celebrate her late husband or father-in-laws’ birthday, both of who were patients to the organisation and serves the teams with elaborate lunch. Bindu does the same, once she bought a new unstitched piece of suit salwar for the nurse, the nurse was extremely reluctant in accepting it and found it too difficult to take it but Bindu did not take no for an answer and insisted. Chetak Sharma and Shyamal Devi invite the team for the wedding of their children but the teams couldn’t make it and they kept wedding sweets and gifts for the teams. They insist on an immediate visit and the team had to increase their number of visits for the day in order to accommodate them. People give gifts, no matter how nominal, in their own capacity. A young man whose father suffered from oesophageal cancer worked in a factory where they made mobile chargers, he built two such chargers for the nurse and the counsellor. Similarly, a patient in remission who was tailor in a renowned boutique and barely had time to breath yet he would take orders from the team members, often the staff members from other teams as well as the organisation visited him and he never turned them back with a legitimate excuse of too much work. Another patients' son works in a footwear factory and once he gifted the team members a pair of slippers each. The team members were visibly embarrassed; the family perceived my presence to be the cause of embarrassment for the team and offered a pair to me in the next visit. My fieldwork ended by the next visit. Similarly, the teams visiting the village areas of Delhi are often given home grown vegetables. Once, a patient asked his wife to bring vegetables from a particular field. He later shared that they did not use pesticides in those vegetables and were exclusively meant for the family members. He added,

> 'How can we serve defected stuff to those who are caring for us, we add pesticides in those ones' (*"Jo humara khayal rakhte hai unhe kharab cheez kaise khilayenge, dawai milate hai na"*).

Some of the village households provided buttermilk (*lassi*) on regular visits. In case of some patients, the team members develop a bond beyond the professional boundaries and are desperate to bring relief. They indulge in small acts of assistance often breaching their professional boundaries to get clothes for their patients, attend family celebrations if the patients insist, go for a lunch invitation, book a railway ticket using internet in utter emergency etc. In most cases, the teams do not share such details with the organisation and instruct the families not to disclose such assistance as such an act is based on personal equations and not a part of organisation's endeavours to bring care.

Similarly, after spending three months in the field and the ‘growing fondness’ of a few of the patient-collaborators, I began to blame myself for selfishly exploiting the emotions of people for my own work. But the counsellors of a few teams shared with me that families notice my absence and ask for me, despite being aware of my role in the team as of a student who is pursuing higher studies/research for a limited period and not contributing to care per se. Some of the teams are of the opinion that these families found talking to me ‘therapeutic’. As one of the patient later said,

> ‘even for the sake of your study, you spend time with me, talk and laugh with me, help the nurse whereas my family leaves me alone at home. This is care for me.’(*“padhne ke like hi nahi, aap samay dete ho, baatein karte ho, hansi-mazak karte ho, ghar main koi nahi hai abhi toh sister ki madad aap kar rahe ho, yeh sab bhi toh khayal rakhna hai”*)

In addition, the families often see ‘being cared’ in a different light. Regular visits, timely interventions, help with equipments, medicines and other consultations are all very relevant but eating at the patient home is observed as a thumb rule for getting acceptance of the household as well as respecting them. The teams are always instructed not to consume anything from the patient houses. But most of the households found it outrageously disrespectful not to offer anything. As a part of our culture, it is a practice to offer the visitor something to eat and drink, but denying it was often seen as discrimination on the basis of caste, class and disease. For instance, I personally never consume tea or coffee. On our visits, we were offered something to eat or drink, usually tea. In such situations, I would explain my aversion to anything sweet (especially sweetmeats, cold drinks and tea). In the early days of my fieldwork, when I politely denied tea I received responses like,

> ‘We are not from the lower caste, we are baniya. (i.e. belonging to one of the upper castes. Also, known as *vaishya*).’
>
> ‘Right now have only this to offer..next time we will bring a cold drink.’
>
> ‘This has been prepared hygienically in a clean utensil and contains good quality milk!’
>
> ‘Don’t worry we use Dettol.’

In order to avoid such reactions, I made a point to ask for any home-made snack salty in taste or a plain glass of water. Later, as I frequented the houses, the families would make sure I ate something before leaving the house. The team members are aware of such reactions given their earlier experiences. They often try to deny any eatables or tea and try to stop people who simply rush from their house to buy bottles of cold drinks (despite dwindling finances), on too much insistence the teams ask for anything easily available at home. In village areas, we are offered a glass of buttermilk, loaves prepared on earthen hearth with home grown vegetables. Sharing their food allowed me to strengthen my ties with the households and provided a window to open up about our lives as well as relishing the hospitality and being cared.

Care: An ethical versus moral dilemma

Kirin wants to attend her daughter’s wedding, observe the festivities and meet everyone before her death, the family and the team decide to keep with her wishes and struggle to make provisions for keeping her comfortable in the last days. She has bone metastasis and is paralysed below her waist due to a growing tumour on her spine. Initial radiations helped to control the growth of this tumour which helped her in living independently for some time but now she is bed-ridden. The thigh bone/femur of her right leg has grown in size due to metastasis which causes her immense pain. She shares her biggest regret as her dependency on her young children. The eldest daughter is of sixteen (to be married) who works as a domestic maid while the rest of her three kids are of ten, seven and six. Her children help her in everything including assisting with the bed pan and attending to her toilet needs. She shares her guilt and sorrow and often sobs inconsolably while talking to the nurse. She blames herself for being unable to contribute to take her own care. She is living in a jhuggi (shanty) cluster. Her husband works as a mason with construction contractors and leaves the house by eight every morning and comes at night. Her children study in a municipal corporation school and return in the afternoon. During these lonely hours, she watches television or sleeps due to the effects of morphine. She keeps a stick by her bed side. Once while trying to assist the nurse (as the counsellor was a male and the patient is immobile to the extent that touching her legs to make space for a urinary catheter would make her wince and shriek aloud) with the catheter, I picked the stick and kept it at a distance from her. When we were done with the procedure, she asked me to get the stick back and I enquired about its usage. To my astonishment and dismay, she shared it was meant to ward off the huge 'coconut-sized' rodents which often climb on her bed.

> 'under the influence of morphine I sleep nicely but am scared of rodent bites and sometimes rodents nibble at my feet and I wake up abruptly.' (*"Dawai ke nashe main neend toh aa jati hai par dar lagta hai, kabhi kabhi toh paer kat rahe hote hain jab main achanak se uth jati hu"*)

After school, at least one child stays by her side to keep away the rodents and help her with anything she needs. Her lack of mobility has led to bed sores and it is getting difficult to move her to different positions. The team has provided her with an air-inflated rippled mattress, an inflated tyre, a wheelchair with commode seat but to no avail. Lastly, her husband makes her sit on a cot (which ideally must never be the case for a patient with pressure sores as per the common logic and the medical guidelines) and cuts it from beneath so that her rear portion can hang from the bed and she can defecate. He ties rags beneath the cot to cover her wounds and her buttocks keeping in mind the privacy and the hygiene. She is finally in a comfortable position, though initially the team doesn't approve of it and suggests them again such a provision but decide to stay quite keeping in mind her comfort in her last days. The doctor shares that she is one of the very few patients receiving the highest dosages of morphine and still suffers from unbearable pain. Till her last days, team desperately tries to control her pain and succeeds to some extent but the bouts of pain often remerge, especially at night. The doctor and the nurse receive phone calls from her family at wee hours in the night when she is unable to sleep. Many people in the jhuggi cluster have heard her painful screams. As one of them says,

> 'sister wreathes in pain, she screams as well sometimes and sleeps after getting tired'(*"didi itna tadpati hai dard main, cheekhti bhi hai kabhi kabhi fir thak kar so jati hai"*)

The team remained largely discontent till her husband intervened with a 'highly inappropriate' method to deal with her immobility, defecation and severe bed sores. While other patients, usually have a provision for biweekly, weekly, fortnightly or monthly visits her case was an exception to the rule with three to four visits in a week.

This intervention was never shared with other teams as it would have been seen as a failure on professional grounds but it remained a comforting effort for her and her family. As the team shared,

> ‘they (other teams) will never understand, more than the teams the people sitting at the office and supervising the home care teams will not acknowledge the ways as these defy the protocols of care giving and other teams would never lose an opportunity to criticise us’.

The team insists that the properness of care work can be understood only by those who are doing it. Kleinman[29] in one of his lectures which emerges from his most recent work (2008, 2010) on care based on his personal experiences as a caregiver to his wife purports a similar notion.

Mol et al. (2010, 13) suggest that good care can have bad effects and hence, the locally relevant ‘good’ and ‘bad’ might not be the case in reality. Many of the patients in remission are often seen smoking or drinking. Usually the teams counsel the patients but in a few cases, especially in the rural pockets where elderly patients are used to *bidi* smoking, the teams are lenient. The idea is to enjoy the final years of life as death is inevitable. This leads to a great camaraderie between these patients and team members. Many patients use Ryle’s tube for the food and water intake after an initial phase of apprehension and shame. In a few cases, where patients come to know about a ‘bad’ prognosis, they express their desire for alcohol. The families, after consulting with the teams, often allow it saying the all wishes must be fulfilled before one dies and a few patients who are on feeding tubes consume liquor using the same. These instances may

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[29] https://www.youtube.com/watch?v=UxosTKujwWQ last accessed on 18 March 2014.

reflect an absolute disrespect towards the clinical way of living and behaving as a patient, as a healthcare team and as a family but during the bereavement visits, the families share no regret and consider this level of acceptance on the part of the teams as it was a heartfelt care, no one said no for anything (*"mann se sewa ki, kisi cheez ke liye mana nahi kiya"*). As an old lady in her late seventies from a village in Kanjhawala, who used to smoke bidi, said

> I can smoke, right? (Smiles heartily as the team members nod in agreement) This shows you are one of us, doctors are human after all. Life must be lived like human beings and not patients. The clinical (referred to it as *doctori)* ways never improve life, they finish all that constitutes life (laughs heartily)'(*"pi sakte hain? hai ki nahi? Yeh hi toh batata hai doctor hi insan hoye hai. Ab jeena bhi insaano ki tarah chahiye, mareej jaise nahi. Doctori tareiko se zindagi na sudharti, jindagi khatam ho jaati hai")*

Similarly, in their last days many patients requested for a pie, mutton curry, an ice cream and things that were prohibited as a course of treatment and were provided accordingly. Sometimes when good care did not give immediate desired results and the patients or the families labelled it as bad care despite ascribing to the protocols. For instance, a large number of patients, nurses and counsellors confided biopsies as the cause of spread of tumorous growth. These conclusions were based on visual experiences as after a biopsy procedure the tumour used to grow.[30] Later during conversations with doctors in the organisation and other hospitals it was ruled out citing a theoretical possibility but a few

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[30] I decided to ask the doctors in the organisation who rubbished such possibilities and blamed ignorance for it but stated a theoretical possibility that biopsies can induce blood stream spread leading to cancer growth. Nevertheless, many nurses confessed that their experience with the patients would make them think twice before considering biopsy.

nurses ‘confided’ that ‘it is better to believe your eyes than believe in book based knowledge’. Nevertheless they always support biopsies while talking to the patients, as it is the only assured measure of diagnosis and the organisation never registers a patient until such a report confirms the diagnosis. Later, the survivors’ lauded biopsy as a timely check to nip the cancer in the bud while the families who lost their lives to advanced cancer ‘blamed’ the biopsy for the ‘spread of cancer’. Likewise, in case of many patients living with small children and only one care giver, it was difficult to move a bed-ridden patient on a day to day basis which often resulted in pressure sores. The teams tried to provide all sort of resources to manage the sores yet in a few cases it was impossible to absolutely get rid of the sores or move the patient bodies comfortably. In such cases, all the efforts for good care never result in absolute good care but it is neither understood as bad care. There are on-going efforts to do possible “tinkerings” here and there and that makes it a process, a matter of practice till the patient could be in as much comfort as possible. A lot of structural gaps make the situations challenging but efforts on the part of everyone to bring relief to the patient refined care into “persistent tinkering” (Mol et al 2010: 14).

Many of the patients express their dilemma before undergoing surgeries which are in some way distorting the body. The patients with breast cancer and osteosarcoma (bone cancer) share their concerns with the ‘visible’ nature of their bodily loss. During one such interaction, the patient asks, ‘how could being cut and handicapped be called care?’If one attends to this question from a purely clinical perspective, it is a possible curative intervention. But given the social, cultural and economic contexts, becoming a handicap, losing a breast or even fertility due to procedures like chemotherapy often raises newer needs for care of another kind. Patients losing their organs to cancer often shared the sense of being cared for the rest of their lives. For them, the surgical intervention was not a part of care but a door to another world of care. One of the patients, Kavi, who was registered with AIIMS, New Delhi for twenty years shared that he had already undergone six surgeries and the doctor's had advised him a full leg amputation which he refused. He explained that he was a driver by profession who needed his leg to control the vehicle; he either wanted to support his family or die but not be a burden to his wife. He further added jokingly, *'the care I am receiving from my family is more than enough, won't make a deliberate effort to increase my share of care.'* The kind of care that is thus provided is simultaneously making space for newer kinds of care to emerge. In such cases, care becomes a vicious loop and usually individuals are apprehensive to further transitions if given a choice. While most of the people engage in or desire self-care, the bodies tend to be unruly and this often requires dependency leading to a fear of further care. On the contrary, while meeting with survivors with amputated limbs or organs, the procedure of amputation and the counselling for preparing the patient for the procedure was often referred to as best intervention in retrospection. The meaning to what care 'meant' and 'means' vary.

Summarising care in the field

The teams visit families belonging to different socio-economic backgrounds. The patients live in the elite households located in posh residential colonies, the JJ (jhuggi jhopri/ slum) clusters, the resettlement colonies, unauthorised colonies, DDA flats, villages located in Delhi and NCR (National capital region), homeless staying either on footpaths or in destitute and elderly homes. The families and the patients have similar share of struggles despite a differential access to resources, at least at an emotional level. The fear of death and losing the loved one, struggles with physical debility, disability and pain, coping up with the stigma and shame while adapting to the changed bodies (Jain 2013), often deform and dissect in the struggle to survive, are the common threads binding people across the socio-economic spectrum. The final wishes were to die at home surrounded by the loved ones. The academic literature within the death and dying studies (Clark 1993 and Robben 2004) shows that the place of death is a widely researched topic and often the patients express their desire to die at home (Kellehear 2009). In the field, care is often seen and assessed by the formal care providers within a framework that perceives care in terms of either good or bad, enough, less or in excess. The efficacy of the teams is assessed on these basis and the teams, in turn, assess the informal care provider's or the patients on these basis. The idea is to cater to 'quality assessment'. This assessment is similar to the academic pursuits of exploring care by evaluating the needs of those who 'receive' care (Thomas 1993 and Fine 2005). Such an approach often dissolves any agency to the care-receivers and condenses them into passive 'patients'. But are patients really passive, Mol (2008) asks a similar question in case of diabetic patients)?

In some cases, the families in the field chose not to take the patient to a hospice despite the team's constant assertions. These assertions were usually based upon the evaluation of care on the ground of timely consumption of food and medicine, patient hygiene, availability or lack of care providers in the family as well as the intentions of the family towards the patients' wellbeing. In certain cases, the patients request to be shifted to the hospice citing hostility on behalf of families but the family decides otherwise. The team can only advice but the family or the patient are to decide. Families cite reasons like public shame of deserting their sick and lack of a family member to stay in the hospice due to reasons like age, job, domestic duties etc.

The families learn the skills to care for the patient from the team members. The technique to roll a quilt and place the head of patient along with the shoulders on it while rest of the body was in alignment with the bed eased breathing discomfort in gasping patients and patients suffering from lung metastasis. In case of malodours wounds, the teams suggest honey dressings. Usually a tablet of metrogyl is suggested but adding honey is prescribed as a faster way to control the malodorous fungating wounds. Similarly, patients were suggested to gargle their mouth multiple times with a pinch of baking soda added to a glass of water. This was meant to clean the mouth, prevent odour and blisters caused as side-effects to chemotherapy and radiation, as well as develop a taste for food. Both the methods worked very well and were often picked by other agencies delivering palliative care. Similarly, patients and the families were taught techniques to manage pain by sticking to a time table for morphine dosage, to manage low blood pressure by drinking salted lemonade, management of bed sores, cleaning the tube meant to feed the patient or keeping the tracheostomy (an incision in the windpipe made to relieve an obstruction to breathing) clean and covered to avoid infection and tracheostomy tube care, performing manual evacuation of the rectum in case of constipation (which many care givers performed on the patient when the team couldn't visit them), administering suppositories or giving enema, stoma (a surgically created opening in the abdominal wall through which digested food passes) care, suggesting exercises post mastectomy (breast removal surgery) and checking for lymphedema (is a condition of localised fluid retention and tissue swelling caused by a compromised lymphatic system) in arms or legs after mastectomy or penectomy (surgical removal of penis) respectively. All these procedures and technical knowhow are shared exhaustively as the teams depend on the families for ‘good’ patient care. This overlap of the outside with the private space often leads the patients to express their desire to seek care at home unless a ‘serious’ emergency arose. The families acquired a sense of rendering care ‘like the professionals’ which in return made patients trust their families more. In some cases, the organisation recruited the caregivers from patient families in its teams too. Mol et al (2010) deconstruct the prevailing notions of care and address the need to understand care as a practice with its ever changing imagery contingent upon the site it is being practiced at. The personal space, the home, therefore becomes a much preferred site for care seeking as it combines the empathy and warmth of the home and skilled interventions on the part of the family to support the debilitating and the dying.

The reality of daily lives of people living with cancer never solely rotates around the tumours or multiplying white blood cells. There are phases of general debility to extreme discomfort along with the normalcy through routine acts like buying grocery, going to office, attending school or preparing the kids for school. The oscillatory nature of the life world, therefore, makes the patients as well as the caregivers rely on the awareness of being active and non-dependent. In addition, Kleinman (2008) shares his experience of a doctor patient interaction and opines that ‘the structure of training and of service delivery discourages and even disables the art’ (the art of caregiving).

> “I am writing this essay after having just visited a noted southeast Asian hospital where the doctor-patient relationship for patients returning for follow-up visits

> lasts 1–3 minutes—hardly time to ask a few questions, do the quickest physical examination, and write a prescription. Not a place where the art of caregiving is likely to flourish.” (ibid. p22)

The protocol to maintain the ‘continuum of care’ especially in the cases of non-communicable diseases (NCDs’) like cancer, cardio-vascular disease, diabetes etc. is not strictly adhered to in the absence of state provisions. As one of the radiation oncology professors, from a renowned public medical college in Delhi, expressed during the foundation course (organized by CanSup and AIIMS) that doctors or nurses involved in researches usually are unable to follow up the patient, the onus lies on the patient who is in the need of care and in case of a patient’s absence, the case is seen under ‘permitted error’. The focus, therefore, is rather limited to quantified and graphical assessments instead of seeking the whereabouts of a missing or non-complying patient and looking for a provision for rendering ‘care’.

For instance, Sonia is a young woman in her early twenties who has been operated for glioma (a kind of brain tumour). She is one of the ‘cases’ in an ongoing research project (renowned medical research institute) where cancer patients are provided a flour containing multiple food grains and to see the effect of its consumption on the subcutaneous fat content and muscle thickness in their bodies by measuring skin folds using somatometric methods. During my visits to her house with the team, we found out she did not take the food supplement regularly and as per the suggested measurements. On her visits to the hospital, she told the researcher that she had been consuming the suggested dosage. On meeting the researcher, I found out that Kavita was her patient and told her that she was not regular with the food supplement and this could be the case with other patients too leading to fuzzy data. I was informed that she was a drop out case and later I realised that the very research focused on quantifiable data with a scope for error related to absence or withdrawal. But there was no provision to follow up the patients and retrieve a cross-validated data for finding the reasons for absence or withdrawal, the onus was on the patient to visit the hospital where she could be made to sit. On the contrary, the visits by the team members assured regular follow ups and a circumstantial understanding of the needs of the families.

The above discussion was a way to understand the practice of care. The intimate interactions between patients and caregivers, physical as well as spatial, often create liminal geographies (Wiles 2003) for the patients. When formal care enters the domestic personal space, the initial hesitation amidst the professional hierarchies of knowledge and expertise is overcome by the sentiments of need as well as emotional support. These sentiments emerge from the teams efforts to communicate in ways that ensure trust in the family practices and acknowledges their domestic notions of care. The counsellors and nurses are seen to appreciate the families for their innovative efforts in keeping the patient clean, preparing the feed in such a way so that it can be swallowed easily, creating alternatives for their toiling needs etc. The space, thus creates a new model of understanding of ‘care’. The relationships established during the course of delivering and receiving care last for long. Often the patient passes away and the teams remain in touch with the families and for those who survive, the bond continues. It is therefore, interesting to see how death and dying is perceived during the period of care. The processes of dying of the self, of the loved one, of the family member and of the patient are multiple positions from where death is negotiated. While death has its own ritualistic aspects from a culturally defined mourning period to funerary practices (Robben 2004) to state and legal interventions like death certificate and will of the dead, the care performances establish death through banal rituals. The next chapter is to understand the very processes.

In conclusion, I shall add that in their lives care was often about makeshift arrangements and provisions within the available resources in a quest to improve the experience of living while gradually moving towards death. More than looking into what can be provided for, the work engages with the question if the provisional care was suitable to provide a satisfying death, for the patient, the family and the team members. The answers for which can’t be in a simple yes or no but as frayed as the conceptual nature of care is. The unfolding of experiences of care provides with layers of negotiations, manipulations and further triangulations which keeps defining and redefining care and thereby, sticking to the essence of human lives which are complex yet worth pursuing for as long as possible.

4. Living, dying and palliative care: experiencing living while dying and the understanding of death

> "Every man who lives is born to die," wrote John Dryden, some three hundred years ago. That recognition is tragic enough, but the reality is sadder still.
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> "Sometimes the lack of substantive freedoms relates directly to economic poverty, which robs people of the freedom to satisfy hunger, or to achieve sufficient nutrition, or to obtain remedies for treatable illnesses, or the opportunity to be adequately clothed or sheltered, or to enjoy clean water or sanitary facilities.
>
> In other cases, the unfreedom links closely to the lack of public facilities and social care, such as the absence of epidemiological programs, or of organised arrangements for health care or educational facilities, or of effective institutions for the maintenance of local peace and order.") (Paul Farmer 2003: Foreword by Amartya Sen)

As we come to the last chapter of this thesis, I would like to draw attention to the literature on living and dying with the disease of cancer, emerging from personal engagements[31] with the disease. This thesis is about an organization with its seeds of

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[31] While Sontag (1990) lived with cancer and pursued writing, Mukherjee (2011) is a physician cum researcher who works with cancer patients, writes a biography of cancer and received a worldwide acclamation, Anuradha (2005) who served the Indian Information Services in the

origin in a young woman's personal brush with cancer who was pursuing her doctoral degree from Canada. Harmala Gupta, a doctoral student, young mother and a wife, was treated for Hodgkin's lymphoma in Canada and her treatment costs were covered under insurance as she was a student in a Canadian University. On her return to India, appalled by the lack of support to cancer patients she embarked on her journey of supportive care that emerged from a deeply personal politics. Such amalgamation of personal and political reflects upon the way we, the humans, as a collective have tried to understand, explore, fight and give in to cancer, the disease, at our own levels. Not everyone might be able to establish an organization, write a book, make a documentary[32], write award winning non-fictional accounts or an acclaimed ethnography inspired either through a personal rendezvous or a professional crossing of paths with cancer. But anyone who lives up through this disease thinks of the endings in a similar or may be much more thoughtful way. 'Living up through the disease' is the ingredient that adds relevance to these narrative accounts and forms the basic premise for many research works. So many survivors may lead normal lives with any non-existent mentionable achievements yet the foremost achievement for them and many of the writers and entrepreneurs mentioned through this thesis was to live against all the odds or may be to live through these odds as bearers, hosts, witnesses and interventionists. All the endeavours sum up the opportunity

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capacity of an officer and became one of the first few Indian women to share her own experience of cancer in the form of a book(The book is originally written in Hindi and was later translated to English), Jain (2013) a professor of anthropology and a cancer survivor and Gawande (2014) a surgeon who gives a provocative account on the philosophy of life, death and the meaning of health care by incorporating the last days of cancer patients, including his own father.

[32] On such reference is Cancer Katha directed by Vasudha Joshi .A film made on the filmmaker's brush with cancer in December 2008. It explores the fears and dilemmas on what course of treatment to follow, and through music, there are musings on love, death and memory. http://www.psbt.org/. It's freely available on you tube by following the link https://www.youtube.com/watch?v=sWDhhHuDn0Y(last accessed on May 2016)

of life. Those who barely get the time to plan for an end leave behind them a sense of incompleteness for the families to live with[33]. Death therefore is important, as it's relevance becomes important in the wake of experiencing loss of the self as well as of the others.

The earlier chapters explore the modalities of care in the lives of people living with or had once lived with cancer. The external interventions like palliative care services when collated with home based care shape the experiences of those living with advanced cancer. Advanced cancers result in death. The event of death may occur within days, months or take years in certain cases. The care framework in case of people living with cancer sustains living through the uncertainty of impending death and routine challenges of coping up with the infirmities. Such negotiations form a major part of their everyday lives and the present chapter is a detailed account of observed interventions contingent upon routine interactions between the resources and the actors. The choices, values, beliefs and perceptions of people struggling through cancer (both the patient and the care-givers) may be similar or different to people facing similar challenges in other parts of the world. Lack of literature on ethnographic study of dying and palliative care interventions within the Indian context forms the basis for such an exploration in our home ground. In addition, it is imperative for the reasons above that the discourse on death in India is explained on the basis of religious, cultural and spiritual dimensions and cosmological understanding of life. The work of Jonathan Parry (1994), Christopher Justice (1997) and Ravi Nandan Singh (2016) are a case in point. The present work doesn't contradict this understanding for the reasons that authors pursued the notion of death within a religious framework. Their accounts are about the stories where death is

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[33] I shall be trying to explain this by citing inferences based on the field observations.

already an acceptable entity as the people are old, frail, and unable to speak and either half dead - or about to die (Justice 1997). The present study differs from these accounts on three basis; firstly, it is about people living with cancer, it looks into care practices through the palliative care framework in order to understand the negotiation with the idea of death. Secondly, it is not about a religion based understanding of death. And lastly, this study does not explore the palliative care framework per se but uses it to explore care and dying when external supportive care meets the care carried out within the domestic premises.

> "It remains true that the most significant number of empirical studies of death and dying as well as theoretical contributions continue to come from the social sciences and not, rather disappointingly, from palliative care researchers. Palliative care remains focussed on a health services agenda of research that continually promotes a concern with the body, its symptoms and management, and the problem of service design and delivery. Studies of carers remain greater than studies of people at the very centre of the service: the dying and bereaved." (Kellehear 2007: 372)

Before beginning with an account of dying, it becomes a ritualistic necessity to produce the lineage of thoughts about death and dying based on the knowledge sources availed and acquired through the academic affiliations. Regardless of spatial, temporal and cultural distinctions, human societies across the globe fear and unite during the death of near and dear ones. Death as a research interest has attracted the attention of many disciplines like biological sciences, health sciences, psychology, political science, history, philosophy and anthropology (Giddens 2005). Unlike sociology, anthropology has shown a significant interest in death, dying and bereavement since the earliest days (Kaufman and Morgan 2005). Robben (2004) provides a compendium of anthropological literature on many issues associated with death, dying and burial for instance cross-cultural conceptualizations of death (Malinowski, Fabian and Becker), on uncommon deaths and their explanations based on distinction between a magical death and a natural death (Pritchard), on grief and mourning (Brown, Rosaldo and Scheper-Hughes) and on mourning rituals (Hertz and Gennep)[34]. In contemporary anthropology, for the past two decades (Kaufman and Morgan 2005:324) the ethnography on death has witnessed three moments of description based on a focus between ethnographer and death; the first moment where the personal loss inspires ethnography, e.g. Rosaldo (1993); second, where the field experiences of the researcher shape her/his personal engagement with death and moments of grief and mourning; and third, where death as a research interest alters researcher's relationship to informant's lives as well as the entire ethnographic endeavour. Robben (2004) criticizes this fascination of western anthropologists with death which is fuelled only when they step out from their own societies in the search of exotic beliefs and ritual practices.

Malinowski (1948) challenges the psychologically driven notion of death being fearful and reasons it to be based on a belief in immortality which is a religion based explanation to defy, and therefore deny death as the final ending. The cultural exegesis has focused on 'medicine as a culture' far lately in comparison to the discipline of sociology where Glaser and Strauss (1968) were the first to investigate death in hospitals. However, this was an exception followed by a long drawn silence on death as a research interest within

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[34] For detailed citations see Robben (2004) where he has compiled the relevant articles on death and dying to bring up a cross-cultural reader.

the discipline (Giddens 2005:320). The reason for this delay (within anthropology) can be attributed to reluctance in turning the gaze towards one's own society and acknowledging medicine as a cultural concept.

Death symbolizes permanent separation, loss of an individual life, the end of a social existence marked by dissipation of all evidence of physicality. The dead is no more a visual entity given that its presence has been erased from the social canvas. Death posits the dead outside the periphery of social interactions. The reason for death and dying not being one of the central interests to sociology is the fact that death represents the end of any sort of involvement in the social world (Giddens 2005:320). However, a structural-functional perspective locates the significance of death within society by apparently threatening the continuity of a community thereby inconspicuously strengthening its social structure (Kearl 1989:86). Similarly, Bauman (1992:7) argues that people challenge the fear of death through culture and social organisation. He refers to culture as a defiant denial of death in the desire for meaning and immortality. Within sociology macro theorists like Berger and Luckmann (1969), Giddens (2005) and Bauman (1992) have made passing references to death in their work (Walter 1993:288). Giddens (2005) mentions the work of Glaser and Strauss within American sociology, while development of sociology of death, dying and bereavement began in early 1990s' with its founders like Clark (1993), Walter (1993, 1994, 1999) Aries (1965), Elias (2001) and Bauman (1992) describing the ways in which societies focused on organizing death, dying and mourning. The discipline of sociology theorizes death as a lonely process in the modern societies (Elias 1985:8). Elias (ibid. 8) also sees the increasing age expectancy within the modern societies as a reason due to which death gets postponed and the sight of dead or dying people is no longer commonplace, which makes people forget it in the normal course of life. Bauman (1992) refers to modernity as the agency responsible for deconstructing death. Giddens (2005) refers to the sequestration of death as a characteristic specific to modernity where hospitals have replaced the home as a site of death thereby isolating the patient which presents emotional problems for people reaching this stage of life. Madan (1992) states that modern medicine developed in west and has later spread to rest of the world, dominates the everyday lives as well as the death and dying of people to a large extent. In that case India is no longer an exception either. However, if one explores the modern death and dying within India, one finds that hospitals abandon the patients when no more cure is possible (Rajagopala and Venkateswara 2003) unlike in the west where the patient is handed over to tubes and monitors (Madan 1992:427) which strips off the patient from emotional support of the family completely. In both the cases, one observes a mechanical treatment of the dying at the hands of health-care industry, in the first instance by abandoning while in the second, by confining, controlling and isolating.

Berger and Luckman (1971:175) see death as the most important ‘marginal situation’ in the society capable of leading to a crisis and therefore, despite its marginality it is an essential feature of our lives as it requires people to cope with it. They (ibid) consider it an anomie which is the key cause of the problem of meaning as death defies meaning especially if it is a result of a terminal disease or a sudden accident. Walter (1993:266) states that human cultures must therefore be understood as ways of creating ‘reifications’ that keep the meaninglessness and associated chaos deriving from the human loss of life at the periphery. Mellor and Shilling (1993) site the absence of discussions on death within the ‘mainstream’ or general sociological literature and state using the above argument (Berger and Luckman 1969:175) that to ignore death, therefore, is to neglect the universal parameters around which the social and individual life is constructed. Walter (1993:289) adds to the argument by questioning the demand of sociology of death as a specialized branch within the main discipline. Rebuking the beginning of 'thanatology' in USA, he cites suggestions for incorporation of mortality within general sociology in a similar way that 'gender' has been. Countering his own argument, he (ibid. 289) cites Mulkay and Ernst (1991) who are of the opinion that unlike gender, death does not influence our social conduct in day-to-day setting despite a universal awareness regarding mortality. The certainty of death as a reality of our lives is not able to raise fear in our everyday interaction due to its uncertain nature. Also, one must not miss the point that the above argument is based on an understanding of natural death as a result of ageing and therefore, in case of disease like advanced cancer, the mere awareness of the diseased status raises concerns regarding the mortality often influences the social conduct. In such a case, living with advanced cancer and being fully aware of the anticipated loss changes the everyday reality for the patients as well as those around them. Kearl (1989:437) mentions hospices as an alternative to technological death which emerged as a reaction against physician's total control over the final rite of passage. Death is the end point of a journey which is either a result of gradual degeneration of biological symptoms (ageing) and processes responsible for sustaining life or a result of impairment of vital functions due to diseases or a combination of both. Death as a result of ageing is considered a normal terminal consequence of a life process but death resulting because of a disease has varied social explanations based on theology, cultural values, and social changes. It further leads to a distinct experiential trajectory for the patient and the family members who act as immediate caregivers. In case of cancer, in particular, the journey from diagnosis till the end is feared and frowned upon. Sontag (1990:7) in her account calls cancer a synonym for death. This notion has survived for long and despite all the medical advancement, being labelled as a cancer patient is tantamount to hearing that one is going to die soon, it will lead to a crippled vitality (ibid.13). Kaushik (1976) and Chattoo (1984) cite the role of 'individual's cosmization' in order to make sense of the disorder caused by death. The cosmization has its roots in Hindu and Christian orthodoxy (ibid. 1976, 1984 respectively). The process of cosmization has a validating character which transcends the notion of death as a movement from dream world to the world of reality that is beyond the cognition of the 'world' others see (Kaushik, 1976:266). The very reality is based on a symbolic understanding of gods, ghosts and ancestors. With the arrival of modern medicine, these mythic categories have been probed, pushed and eliminated from the scientific understanding of life and death (Chattoo 1984:70). But the realities are based on beliefs and are space specific (contextual) (Madan 1992:429), which implies that demystification of death within a particular cultural space, for instance Indian cosmic understanding of life and death, is contingent upon location of patient, practitioners and family members. Therefore, within an interdisciplinary model of care like palliative care the exchange and corroboration of the contextual realities posits a ground for potential conflicts between the actors as well as challenges the notion of self. As modern medicine has contributed to demystification of death (Foucault 1976), palliative care, with medical knowledge as a part of a larger structure, is also susceptible to a creeping dominance of medicine.

However, leaving the idea for further speculation, the present research seeks to observe the subtle play of inter-subjectivities as people live while dying.

As stated earlier, this chapter is about the dying and their interactions with the care practices while acknowledging the approaching death. Justice (1997: 12) refers to dying as a social category in his ethnography of death retreats in Kashi, India.

> “The very category of ‘dying’ is a social one: the length of time someone spends in it and how it is shaped depends on how it is defined. Cultural ideas of, for instance, what is a good or a bad death are implicit in the physiological dying process.”

In the similar vein, the present work also documents the family’s understanding of the condition of the dying and their subsequent negotiations with shifting realities as the death approaches. The work analyses the role of organisation during the process of dying and therefore, suggests to supplement an alternate dimension where dying is understood in a more organic and raw form instead of a cosmic peregrination. The chapter delves into the intrinsic details of the processes that prepare the people to acknowledge dying in their personal intimate spheres and care activities are found to play a key role here. In addition, I analyse the role of these interactions in making sense of death while dying.

Here is a note from the field diary to make sense of the field while experiencing dying in the field or the moment of release, (“*mukti”* as so many families and the teams referred to it).

> ‘Each passing day has made me witness the quest between life and death as a journey with no destination as at times death is not the final milestone instead a point of release, a moment where the suffering ceases to be and an experience

> with its certainty cocooned in an uncertain frame. It is the anticipation rendered by the uncertain frame that inhibits the positivity, humans always dwell in the future. One experiences this only in the times of ordeal threatening ontology...existence is endearing, more so when one is aware of the demise. The precariousness of life is taken for granted; one needs soul stirring to grasp it. Some experience it by undertaking the voyage while others try to comprehend it by witnessing those already on the odyssey while so many others never really allow it to seep in. It is never a desired experience instead serendipity. Why fear death as an end? Is it really 'the end'? Are we so used to the presence of breathing, bodies gushing with blood that memory never really garners a respectable place for itself? Or may be it does? Is life signified through breathing to an extent that the reliance on physical senses is all what enables us to feel life and be alive? Is there such a thing known as living as a memory? Thesis writing is a tumultuous affair between the poetics, the prose and the politics, yet the researcher survives to tell the tale.’

This was written after two patients had a relapse and the desperation and discomfort they experienced while sharing the ‘news’ to the team in their next visit. This is to highlight that the meaning making process was mutual, if the patients were trying to grasp the reality of slipping life, the teams observed similar dilemma for the needs of the patients whereas I was trying to sail through my role as an observer-researcher. The magnitude as well as the tenor varied but the situations give rise to taking steps towards the preparations in the event of death. Death barely comes with a date, but, in the field, the acute awareness gradually pushed the patient, the family and the care teams to gear themselves through their everyday interactions. This awareness comes medically as well as physically. Many people in the field dismiss the institutional awareness after an initially overwhelming reaction but physical suffering re-establishes the notion of ‘nothing can be done’.

> “Academics who frequently theorise suffering have also observed that at its existential root it is about grief and loss. Suffering is a state of distress that threatens the very intactness of a person. The anthropologist Clifford Geertz supports this view by arguing that serious suffering is a response to the threat of dissolution to a meaningful part of identity or lifestyle. What could be a more serious threat to identity than the threat of death?” (Kellehear 2015: 17)

When a treatment shrouds the possibility of positives, patients are the first to ‘feel’ it. For strange reasons many patients raise concerns regarding the life expectancy, unfinished matters of the household, reconciliation with angry friends and relatives. Kubler Ross (1997) elaborates upon similar perceptions and fears in case of her patients. The family members ask them not to allow inauspicious thoughts. Their doctors inform them that nothing can be done. And the team members hear the same clichés every day. When the patients utter this phrase in the next visit they share it with much pain. This pain is often overwhelmingly expressive and at times inhibiting to the extent of feeling dejected and the patients oscillated between the two poles of articulation of thoughts. The stories of two patients mentioned below illustrate their experiences as they proceeded towards death. The descriptions are about their poor prognosis and their concerns.

Parimal has oral cancer and is in his early fifties, a coolie (porter) who worked at a railway station. He is a resident of the Savda-Ghevra[35] slum resettlement colony located in the north-west outskirts of Delhi. As the organisation's vehicle stops in front of the park near his house, his goats climb up the car and sit perched on the top. He comes out running calling for the goats and sees us. As we are busy taking out his supply of medicines, a torch and his file, he shares with the driver that one of his goat has been stolen as the Muslim neighbourhood awaits Eid celebrations. The driver, a well-read man with an appealing personality, whom many households often confuse as a doctor or a counsellor but never a nurse (because of the general perception of women as nurses) or a driver 'given his charismatic personality' assures him that he is keeping a watch on the goats. This is my very first visit. As the team introduces me and settles downs in the one room accommodation, he switches off the television. He begins to talk with remarkable gregariousness, laughs heartily and when he comes to know that I am with the team to 'study the impact of cancer on daily life' he shares that his ordeal is most likely over. He says that the treatment was a bigger ordeal than the disease and shares that radiation therapy (referred to as *"sikai"* which inHindi means fomentation or a poultice.[36]) has killed his taste for food, affected his hearing and caused a lot of discomfort. He used to

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[35] It is one of the seven resettlement colony in the out-skirts of Delhi built to house people evicted from jhuggi jhopri clusters (JJCs') located on the public land. Many scholars call these resettlement colonies as 'planned slums' due to the lack of basic services as they officially remain marginal. For more information on this read Shahana Sheikh, Subhadra Banda, Ben Mandelkern. 'Planning the Slum: JJC Resettlement in Delhi and the Case of Savda Ghevra' A report of the Cities of Delhi project. Centre for Policy Research, New Delhi (August 2014).

[36] No one in the field had a clear answer to why radiation was referred to as *sikai* in the hospitals or by the teams. In case of village population as well as city dwellers belonging to lower middle class families and middle income group both educated and uneducated replaced radiation therapy with this hindi term *'sikai'*. In common parlance, as a patient shared, the rays from the machine heal the tumour by warming it and killing the germs. Some of the team members shared that every one understood and used this term 'may be for the reasons that people understood radiation is warm and its warmth acts as as a compress for the tumour'.

smoke *bidi* and shares that now he has stopped smoking it and jokingly adds that this is a 'government's plan' as it wants to make money by selling tobacco as well as by treating cancer, do we get free medicines? *("dawa kahanmuft milti hai")* .

I smile and tell him that he is very smart to understand this conspiracy, to which he adds,

> 'understood, but its already late, the disease[37] developed inside. Doctor's have provided the treatment and are giving medicines too. Many people couldn't tolerate the medicine and died. Let us see, everyone is trying in their own capacities.' ("*samajh toh aaya par der ho gayi, bimari ban gayi ander. Doctoro ne ilaaj toh kiya hai, dwai bhi dete hai. Kayi log toh dwai se hi mar gaye, jhel nahi paye. Dekho kya hota hai, sab koshish toh kar rahe hai.*")

I am visiting him for the last three months now. It's a cold January morning, as I reach the office. The nurses and counsellors from both the teams are taking turns to call the patients for scheduling the visits for the day. The doctor is looking at the files and as I reach he asks me if I know Parimal from Ghevra. Apparently, he called the doctor last evening to share a bad news, the doctor shares 'relapse *ho gaya*'. The counsellor shares that they are planning to go to Savda. I ask the other team about the patients they are planning to visit, the nurse shares 'not many you know'. I decide to go Savda. As we meet Parimal standing at the door of his house, he asks if we want to sit inside or out in the Sun. The counsellor suggests outside and he picks two chairs while I along with the counsellor pick one each and put them on the ground. The counsellor asks him if he went to the hospital and he shares his 'unfortunate'[38] prognosis with a shivering lower lip,

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[37] The term disease was mentioned as *bimari* in the field. I would like to mention again that all the conversations with the patients were either in Hindi or in village dialects which were close to Hindi and comprehensible to me.

[38] Mentioned it as "*buri khabar*"(i.e. bad news)

almost choking while trying to speak pretending to hide his tears by staring into the ground instead of looking at the team members or his wife or me, he runs inside his house on the pretext of bringing a medical report when he isn't able to restrain his tears. We see small round wet patches marking the tear drops fallen on the earth. The nurse opens her file and exchanges a look with the counsellor with pursed lips as if trying to share another disappointment. The counsellor gets up from her chair to hug his wife who is in tears and standing next to the door. The wife sobs cautiously looking behind to see if the husband isn't back yet.

After the disclosure of a bad prognosis, in the subsequent visits the teams find him quiet and depressed. He keeps a mirror by his bedside to see the cancer growing out into his mouth. Initially he is unable to speak clearly and has pain in swallowing his food too. In one such visit, the nurse asks him to open his mouth to show me the tumour protruding into the oral cavity. He looks grim and keeps staring at the floor of his house with moist eyes. The nurse asks him about his pain and bowels, if he is eating properly and he keeps nodding his head unable to reply verbally. He holds his throat and squirms and lifts the glass of water and indicates the nurse through hand gestures that he is unable to drink. The nurse talks to the doctor on the phone who is with the other team today and suggests him the dosage accordingly. The doctor suggests going for an intubation in case its getting difficult and the nurse shares this information with his wife and him. As he shakes his head vigorously in refusal, the team asks his reason for inhibition. The team is aware of such apprehensions and sensing it the counsellor further prods. Does he worry about people's reactions? The wife agrees smilingly, he refuses again using his hand. The counsellor informs him that the tube will help him in eating without any pain. For now he can open his mouth with great difficulty and since the tumour is growing fast it can lead to a complete obstruction. He gestures that it's fine and then hints towards the sky, the counsellor asks him to write it. He writes that by then he will die. The counsellor suggests that death doesn't come easy and it's not advisable to think of death but think of measures to make life easier for regular activities like eating. He doesn't respond. The counsellor asks him to share his concern but he nods his head in denial and joins both of his hands together. Earlier, he has shared the poor economic condition of the family and finds it difficult to regularly visit the hospital for the follow ups. Neither his daughters nor the wife are literate and his brother's have withdrawn all kind of support. One brother and his wife visited them to offer a price for his share in the ancestral land in his village in Uttar Pradesh, Sitapur. He shares that his brother's wife mentioned that since 'he has no son and only a handful of days, he must sell the land to support his wife and daughters'. He has signed the papers but has not received any money. He says that if he survives its fine, otherwise leaves it to the destiny of his daughters. In one such visit I ask him about 'his family caring for him and if he has any fear'?

> 'My wife and kids take care of me; I worked in my capacity till I could and now it is their turn. My condition is better than earlier, now let us see if it gets cured or not, doctors are doing their part, I am doing mine, lets see what happens. What will I do fearing death; if this is how I have to die I will die this way. Fearing it won't help.'

I couldn't visit him in his last days and the nurse shared the news of his death with me when we met at the head-office. She shared that he was in great discomfort, unable to open his mouth, one day he put his hand inside(*"bohot pareshan tha ab toh, muh bhi nahi* *khol pata tha, ek din toh haath dalke")* and thengestures me by directing her hand into her mouth as if trying to extract something from the inside. I ask, a little horrified, did he take it out? The nurse nods but the doctor is sitting besides us, he smiles and says in a matter of fact manner, that this was not the first case, earlier also patients have done that and he moves his hand towards his mouth imitating the nurse while reminding me of a patient in the destitute home who had ripped his tumour in a similar way. And I ask, 'then'? To which the doctor replied, 'then what? He was comfortable. Carried out his surgery on his own, he was intubated ("*Apna operation apne aap, tube toh lagadi thi*").The nurse further shares that he was getting his feed through the tube but the discomfort of the bulging growth made him take such gross measures. He knew going to the hospital meant spending more money, it was already difficult to manage day to day expenses, so he stopped going to the hospital and asked the team to keep visiting him. They would have visited otherwise too. She informs me that he passed away in the next few months.

This is not a singular case but a reflection of life conditions of many people in the field. The teams and these families are a small world on their own. A number of families report lack of social support after cancer and the people express their actions and emotions to the team members for the reason that the teams accept the patient and families autonomy to decide, to make choices and to share them openly without fearing judgment or any kind of patronization. As a counsellor shares, 'we are from an NGO, we know people can throw us out from their homes. Many families have refused our services too. So we make sure that we can help the patients as much as we can, still there are situations where either the family or the patient decide against our visits. But we need to stick to the work culture which matches the corporate services and is public (*sarkari*) in structure, free of cost'.

Parimal's neighbour Mahsoon, in his late twenties, has four children and a wife who works as a domestic maid to earn for the family. As I enter his room for the first time, the overwhelming stench hits us. He is lying on a makeshift bed with the room smelling of pus and flies swarming around. Just below his navel near the pubic bone he has a festering surgical incision. As all of us sit there, trying to control our breath and get used to the stench, his wife enters the house. She openly asks if we think the room smells bad. He looks at her. The nurse senses some tension and asks his wife to show us his medicines. He says he has been constantly changing dressings but the discharge is incessant. The nurse checks the medicines and sounding a little annoyed asks the couple to strictly decide who is going to take the charge for medicines. He has not consumed the dosage that would have dried up the pus by now. He complains and blames it to his wife. The wife smiles but looks confused and the couple begins to argue. The nurse asks them to be more particular listening to which Mahsoon says, she knows I can go either today or tomorrow, so how does that matter("*isse pata hai aaj jayega ya kal, toh kya fayda*"). The argument stretches while the counsellor moderates and asks him what makes him think that he is going to die soon. Sniffing while shying away to make an eye contact he points to his wife and in a heavy baritone says, 'ask her' ("*isse pucho*"). The nurse looks at me and hints me to come out and asks his wife to join us as we forgot the gauze in the car. As we move out, his wife is trying to explain to the counsellor who is negotiating the argument between the couple. The nurse takes a deep sigh making me presume that this was a way to dodge the foul smell. We wait for the wife and the counsellor as the nurse discusses the lack of concern on his wife's part and the horrible smell emanating from the wound. They come out after sometime. His wife shares that because of the putrid odour they keep a distance from him and softly whispers, 'what if the disease spreads out' (*"phail gaya bimari toh"*).

He was operated for colon cancer and uses a colostomy bag now. His house is a room with un-plastered walls showing the red coloured bricks and a roof of asbestos sheet. With no storage space, the beddings are stashed in a corner, the kitchen equipment are spread out in one corner on the floor, the washed and unwashed clothes are hanging on separate plastic ropes and three wooden planks have been joined to form a bed which occupies the entire space in the room. In my first visit to this place, the driver of the team informs me that people from this colony come from lower economic rungs of society and many of the inhabitants are masons, construction labourers, rag pickers, domestic maids, butchers etc. I witness the grim poverty as we travel through the lanes with women sitting outside winnowing wheat, sifting through the dal, chopping vegetables, the televisions loudly playing Hindi film songs and the dialogues from soap operas, old-men smoking *bidis* squatting in a circle to play cards, semi-naked children either playing around or rag picking, some people gathering around the mobile toilet facilities and the water ATMs installed by Delhi Jal Board.

As we reach the corner of a disheveled park, we see Mahsoon's children taking bath outside, near the hand pump. During the winters, he can be seen lying down on a cot to soak up some sun. In later visits too, I find the nurse asking the couple about unused medicines given in the last visit and they start arguing in front of us trying to put the blame on each other. He does his dressing by himself and the wife keeps away the scissor to hide it from the children who might use it. She still fears that the children might contract the disease; she doesn't touch it herself too and uses a cloth to pick it up. Overtime, Mahsoon is used to this discrimination and often complains that the situation will last till he survives. The team explains her on every visit that cancer isn't a communicable disease, she smiles every time and follows the same practice on subsequent visit. He wears an amulet (*taveez)* around his waist given by a healer from the local mosque. He shares that care is carried out only if there's hope (hope to survive) (“*wahan dekhbhal hoti hai jahan umeed ho”*).

In one such visit, I try to audio recording him; he gives his consent but sounds reluctant to share much. During this conversation he keeps hiding his eyes with his arm on his forehead while lying on the bed, as he answers questions related to isolation and future prognosis he gets emotional trying to control his tears. With moist eyes and shaken voice, he shares that he is of no use for the family who are busy with their own lives. Calling himself a useless- (“*bekar*”), he dejectedly shares that no one, the children and the wife, sit with him to talk and only his mother cared for him when she was around.

> ‘Three years ago I had an abscess (“*sundi/ foda paka tha”)* and came to know of a tumour in the rectum (“*gaanth latrine ke raaste main*” i.e. a knot like structure in the passage of stool)..it was diagnosed in Nainital. Then came to know about the incurable problem (“*lailaaj bimari”)* and stopped medicine, was referred to the hospice. I used to sell chicken and fish but not anymore. I want god to call me to his abode (“*khuda apne paas bula l*e”). Had I been fine the family would have wanted me. Now I feel giddy and weak. Either I should die or get better. Everyone is enjoying in their own lives; no one bothers..watch tv, no one sits to

> talk, everyone busy with tv (repeats himself), my mother used to care for me but she had to go to village to look after the house. I don't have any work to do, I am a useless (*"bekar"*). Everyone has to die, so that's ok, fearing it will not resolve it but I shouldn't stay hanging in the middle ("*Marna sabko hai, dar se to much nahi hoga par aise latakna nahi hai, ya theek ho jau, ya mar jau.")*

The team feels he has given up on life. They talk to his wife about it and suggest her to spend some time with him; she keeps smiling and replies,

> 'The disease will spread; we give him water and food ourselves. The children don't eat food if he touches the utensils' ("*hum khud hi khana paani dete hai, bache hai phail jayegi bimari. Bache khana nahi khate agar yeh chu de bartan")*

C: (sounding a little desperate) But we have told you so many times that the disease doesn't spread, had it been so we would have contracted it first.

N: (Interrupts the counsellor and adds) didn't you notice how doctor *saab*[39] squeezed the pus from his wound and moreover, that wound isn't cancerous. It is an infection of the surgical incision ("*taanke ka zakham hai, cancer nahi hai"*). Why don't you take him to Shanti Avedna, the hospice? He will be cared better in his last days.

His wife smilingly nods and the team members' conclude that she would never pay heed to this no matter. This leads to a casual conversation and the team shares that Mahsoon wouldn't die 'comfortably or at least with dignity' as he is always alone in his dilapidated and cluttered room with 'no one to accompany him but the houseflies'.

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[39] a short form for 'sahib' i.e. Sir. The oxford dictionary mentions it as sahib |ˈsɑː(h)ɪb, sɑːb| (also **sahab**), a noun used as a polite title or form of address for a man: *the Doctor Sahib*. Irrespective of the 'politeness' referred to in the dictionary meaning, the term presents a hierarchical connotation. No nurse of counsellor has ever been mentioned as 'sahib'; the term was used with the doctors and was found to be gender neutral in their case.

N: No matter how much you explain she keeps smiling. *(“Kitna bhi samjhao hanste rehti hai.”)*

C: She doesn’t care; she knows he is going to leave soon. (“*Isse farq nahi padta, isse pata hai yeh jaane wala hai*.”)

They further add she will marry his younger brother once he dies and blame the blooming relationship for her negligence towards Mahsoon.

Mahsoon, in one of the last visits, after the family took him to the suggested hospice and brought him back a week before he died, had shared his awareness of the relationship with the team and sexpressed that he wished *allah* to end his woes soon so that others will be able to live happily.

Both the cases are similar in terms of their anxieties and awareness of their own death. They cry, sound indifferent in their communication with the teams after their bodies begin to show signs[40] of decline and a confirmed prognosis by the doctors assures them of the awaiting death. Moreover, their social realities, of relationships coming to an end, their anger and sorrow over the waning interactions make them acknowledge the impending death.

The purpose of above illustrations is to present the multiple engagements in the lives of a dying person. There is not a single moment that introduces death, instead its communicated through everyday actions and reactions from the family, their concerns and their indifference both act as indicators. The precarious condition of the patient

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[40] Many patients saw the increasing weakness and the tendency to stay in bed due to the physical debility as signs of the nearing death. They could be seen asking questions to the team about how much time were they left with? The teams would answer in ambiguous and realistic terms, ‘we don’t know about ourselves, how can we speak for you’. Gradually, with an increased participation in the field, I would answer in similar terms when the question was directed towards me as it was difficult to dodge the enquiries every time by citing myself as a student pursuing higher studies.

makes her/him more vulnerable to these expressions. The care practices or the perceived lack of them instills newer meanings to the understanding of the sick and this realization makes them, in return, live and act in particular ways. The above accounts have been juxtaposed with findings from observations, casual conversation as well as open ended interview recordings to cite the assimilation of social, economic, emotional and physical factors which constitute individualistic dying and hence, may not be a parameter for multiple deaths observed due to cancer. I propose dovetailing of the individual accounts for the purpose of narrating the story of the dying collective. The intention to keep the specifications as stark reminders is for the reason that the discipline of anthropology is known for its tendency to generalisation. Kellehear (2015:17) shares that Kleinman ‘doubts this (individual instances) leads to social changes that can help others, yet if personal understanding changes one’s perspective, that is a social change in itself.’

> “greater understandings come from these small connections and corrections and are themselves prerequisites for broader social, cultural, and political changes in our world.” (ibid.17)

The individual accounts from the field are not disparate and share a generous amount of overlap in terms of understanding certain phenomenon. Mass deaths either lead to fundamental alteration or a complete destruction of an entire social system, more so if the cohort involves socially critical individuals like members of a sports team or a team of experts involved in project of national or global relevance etc. (Kearl 1989:84). The present study, however, focuses on individuals who are to die soon. Individual deaths impact a smaller group, like a family where the brunt of the death is borne by a smaller collectivity. In a smaller group, the contribution of the individual is more unique in terms of its relevance to the group's members as well as its overall sustenance; therefore, a single death has greater ramifications (ibid.84). The life conditions may vary yet the notion of death, a great leveller as it is commonly known, emanates a sense of unification. The difference in economic and social status bears less impact on the perceived wait of impending death. Even in the case of survivors, the acknowledgement of the disease during peer support, in the interactions between volunteers and the patients in the day care facility this sense of sharing a common ground often resulted in empathic embraces. The common ground is not cancer but what the disease entails to. The families share their concerns, hard work and toiling whereas patients have their share of pain, suffering, strength and dilemma. The forthcoming account must not be seen as a conglomeration of individual ideas but the inter-linkages I am trying to provide. There are no strict universalities of dying and the work attempts to present the mayhem. I add it as a constant reminder all through the narration to remind ourselves that dying is a conglomeration of incertitudes'. The presentation does not focus on dying but on living while dying and therefore, the experiential illustrations form a basic pedestal to develop an understanding that may hold relevance for all of us.

> "While it is true, Heidegger emphasised, that no one else can die my death, there is a sense in which others can share my dying (Heidegger 1962:303)." (Kellehear 2009:147)

The above two accounts are based on the interactions for over four to five months. The ever emerging acknowledgement of the awareness of death as a finality is a key point. Kellehear (2015) in his account of the dying people and how they perceive death while observing near death experiences chooses selectively. He tries to stick to 'more natural' experiences of dying uninterrupted by the processes of waging or terminal illnesses and uses the phrase ‘the social life of the dying’. While he draws analysis on the ‘inner lives of the dying’ he does it by steering away from those dying due to terminal illness. Instead he incorporates the experiences from literary sources where people have stuck in conditions like war, accidents and ageing. He has carried out extensive research in the field of death studies (2007) (2009). In ‘The Social History of Dying’ (2007) he reminds us of overlooking the art of managing death. He calls the modern dying as a stark reminder of economic disparity, increasing age, migration, exclusion and isolation engendering social disquietude. The diseases and medical science stand at a lower wrung as social features accounting for the shameful forms of dying. This chapter also builds upon the dying in poor living conditions in similar respects. Cancer, the disease, is seen as the cataclysm spiralling the downfall.

> “I am not concerned with the increasing number of people who have advanced disease, commonly a spreading cancer, who will not acknowledge to themselves any notions of death or dying. These people are not dying in any sense other than perhaps a medically observed one. Such people often view themselves as people living with serious chronic illness. They are, or aspire to be, survivors to the end.”
>
> (Kellehear 2015:Preface)

The above quote can be easily attributed as a western understanding based on early screenings and longer survivals (Jain 2013). The field reality in the present case was barely close. As a developing country we lag behind due to late screenings which result in more number of advanced diagnosIs, lesser awareness regarding the disease and its care, not only among the families but the larger medical fraternity. The basic requirement of morphine is neglected in many regions, even states across the country. The fear among the doctors and nurses reading administration of morphine is well accounted in the Indian accounts of palliative care literature. The doctors tell that patients that 'nothing can be done take them home' but barely instruct the families on how to care for the patient. The organization introduced me to innumerable households sharing their plight of trying to care. Hospitals cannot care for such a huge populace, it is the families they need to rely upon but the families are undergoing a severe crisis, the crisis of managing the dying and the organization supported this quest of the families. But dying takes time, the calculations begin much before the onset of debilitating symptoms. And in cases where patients pass away without strong symptoms of infirmity, the family goes berserk. In one such case, we come to know that the family in a village located ahead of Najafgarh wants to meet the team only a day after the patient's death. There is not much communication over the phone but the nurse and the counsellor sense distress. The counsellor talks to the nurse and suggests her to keep all the information regarding morphine with her. We have to cross fields dividing the village from the border of the Delhi state. The counsellor asks the driver to stop so that we can cross the fields on foot. We go through the trails diving the fields and as we reach the village boundary we climb through a trail on a mud-mound covered with dung cakes. I am enjoying the natural surroundings unaware of what lies ahead. As we reach the village, there is a tent outside the house. There is a gathering of close to a hundred people who are there to mourn the deceased. As we sit inside, a few relatives including the daughter of the deceased come charging towards us asking the team members about the medicine (morphine) that was suggested a day ago. The counsellor takes the stage and tries to pacify the angry family members. The elderly members in the family ask the daughter to stay calm. The nurse adds that many patients consume this medicine and the dosage was never too high. The daughter begins to narrate that the family called the team nurse and asked if they should take the patient to the hospital. She further adds that the nurse refused stating that it he might have been sleeping due to sedation (30mg BD) after consuming morphine. The nurse counters her that she suggested to call for a doctor nearby before going to the hospital which is too far. The family begins to counsel the daughter using phrases like it was time (*"samay aa gaya tha"*), who can dodge the destiny (*"honi ko kaun taal skata hai"*). Hearing this the nurse shares with everyone that the family was aware that the disease had already spread. The daughter intervenes adding that her father looked hale and hearty from outside, he had no symptom apart from pain. The team shares not everyone dies a similar cancer death. The family consoles the daughter by appreciating the 'clean and quiet' death. As we walk out through the field, the counsellor jokingly adds that he suggested the driver to stand on the far end so as to escape the wrath of the angry 'jat' population and expresses his dismay over nurse's decision to prescribe morphine a day before the death. The decision of prescribing morphine is never taken by the nurses solely and the doctors need to assess the situation. In this case, the doctor was suggesting morphine for quite sometime both of them suggested it unanimously. This incidence on one hand illustrates the expected stereotypes of dying and death due to cancer and on the other, the acceptance of death on the grounds of the quality of death. The role of the process of dying becomes crucial to acceptance of death.

Accepting the diagnosis and pursuing treatment

At the very onset of her account, Jain (2013) mentions ‘a concrete fact’ in her introduction that ‘cancer can kill.’ In India, the late screenings often result in more deaths due to cancer. In such a situation, when patients came to know about a confirmed diagnosis, the initial thought is of death as so many of them shared in the field. As the families confide in making all possible attempts to save the life, the patients see their treatment process as a leap of faith.

When Hasan in his early sixties is diagnosed with the cancer of oral cavity, everyone in the family including him spring to action; to procure resources for treatment, selling the farming land, stalling the construction of the house, embracing the severe physical reactions of radiation and chemotherapy and focussing on treating the ailment as he shares,

> ‘we thought let Allah decide[41], my entire mouth has been red with ulcers for last so many months. The pain makes it difficult to sleep or swallow water but I pray. Even *paigambar* (Prophet) had his share of struggles. The doctors in the hospital (a public hospital) are good and my family cares for me (smilingly pauses for a few seconds) I do not need much’.

A lot of patients and families are never aware about the prognosis as the disease advances, and the teams’ pitch in to prepare the households with every next phase of care. The needs of cancer patients vary with the advancement of the disease and the team

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[41] Death was never mentioned directly. In certain cases I asked the patients directly, often during the casual conversations, given the level of comfort we shared while communicating. It may sound unethical to western schools to begin with a mention of death but the conversations were open. The team members knew how and where to raise the question of death, as it allowed the patient and families to prepare for it, become aware of the prognosis and make spiritual, emotional and even material preparations for dying. It was not a taboo in cases with advanced prognosis. No one waited for the death but were acutely aware of its unpredictability which provided them to make provisions as well as settle scores, both external and internal.

members within their capacities of a nurse, a counsellor and a doctor observe the declining health and make people aware of the next step. It is a continuum of advancing cancer symptoms and a continuum of care that marks the life course of the dying individuals. Dying as a process comes into play through varied kinds of representations within the care frameworks. The meanings entwined within this process are understood through three positions, namely, of the teams, of the family members and of the self. The discussion is based on the interactions around the event of anticipated death and the way the idea of death is initially acknowledged and incorporated in everyday conversations and practices. Some sociologists believe that the sociological analysis tries to distort the complexity of death. As Craib (2010) shares that a sociologically driven analysis fragments death and dying into matters of burden, sequestration etc. much to the chagrin of the everyday knowledge and the essence of experience is snatched away. The conversations below explicate the awareness of dying through such experiences in within the homes instead of hospitals.

Living and dying amidst routine conversations of death

> "Dying should be defined as the personal expectation and acceptance of death as an imminent event." (Kellehear 2015:9)

A conversation between two neighboring patients, Suresh and Ramila, when Ramila's brother died untimely due to an undiagnosed fever. Suresh is a paraplegic with metastasis all over while Ramila suffers from the metastasising cancer of gall bladder.

> *Suresh*: My wings have been plucked. It's the tongue that doesn't stop, so what to do? Now I shall linger in this condition. Understand, one needs to make a mental note that one day each one of us has to go, some one first while the other next, but no one is permanent.
>
> *Ramila*: (I) Have been fighting this ailment for the last three years and he (referring to her brother) passed away before me.

This thread presents expectations as well as acceptance of the terminal diagnosis as well as the reflection on the event of death. On one hand, both the cancer patients mourn the 'unexpected' death, they ponder over their own conditions which they already presume to be fatalistic in nature. Ramila shares that doctor in her last visit shared that the disease has spread ("*bimari phel gaya hai*"). Suresh is aware of his terminal prognosis too. The conversation represents their preparation towards the idea of death, a notion rooted in their existential order which silently establishes the process of dying.

Similarly, Mitali, a thirty eight year old woman who was in remission for the last three years (I met her in 2013) and underwent a mastectomy, mentions cancer as a 'constant threat for it leads to death unlike cold and flu'. She wants her son to finish his studies and start working before she has to leave.

> '(I) am not at all afraid of going; I only worry for my son who is still young.'

Death is for the society to feel, observe, mourn, and express upon whereas dying is more intimate as it has direct implications on the person who is perceived to teach his self to abandon the notion of living. Dying, therefore, is a struggle of the self with the self. As Wellmott (2000:652) puts it,

> “anticipation of death remains a major existential issue and therefore, signifies a projected loss more than the real loss”.

There isn’t a particular momentthat demarcates dying unlike in the case of death. Kellehear (2015:9) suggests a fluid identity of death which is context-dependent and keeps fluctuating. The bodies are giving obvious signs of wearing away gradually and the patients are the first one to read them. As Prema would say, ‘I don’t know when the time is going to come, but I am ready’. The nurse has been visiting her for over eight months now; it has been two months since I started visiting her. The nurse mentions that since early on Prema keeps mentioning about her death, she has told the nurse that in their next visit the team won’t find her (as she will be dead). Later, she shifts to another rented accommodation and changes her phone number without sharing it with the team. The nurse worries about her whereabouts, the earlier landlord gives us the contact number of her husband and when we visit Prema (P) again, she shares that,

> P: It has been so long, I am still alive. This body makes me feel everyday the end is near, but I don’t finish. I cannot do anything, the children try to cook but they are so young. Look at the stomach, it is so swollen always (due to ascites[42]).
>
> N: Why did you hide your location?
>
> P: Your medicines help me with living for more time. Now tell me, for how long? It is unbearable. I don’t want to disturb you; you can help others, why waste your time on me?

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[42] a painful medical condition leading to accumulation of fluid in the stomach.

> N: It’s not how you think and the medicines are for controlling your pain. We are here for people like you and what about the kids? (Two children aged 5 and 7)
>
> P: What about them? I cannot stay forever. God will think about them, I have stopped thinking. (The young children sit by her side and intently listen to their mother; the nurse feels sorry and pats the young girl’s head.)

Later we come to know that she passed away after two weeks. In her case, she feels the nearing death through her on body and has prepared herself for the death. The nurse expresses pity as she shares that most young mothers cry for their children till the very end unlike Prema who has decided to ‘let go’.

It is observed that during the initial process of dying the mere mention, indirectly, of death to the patient often results in uncontrolled emotions but as the time proceeds talking about death becomes easy. The actual moment of death cannot be explained by the deceased but thinking about it is found to bring a sense of loss of identity. Kellehear’s (2015) examples are about people who were close to dying, a soldier fighting in a war zone, a man attacked by a ferocious carnivore etc. In the field, though, every time a patient experiences discomfort they are rushed to the hospital. These distressing experiences are a part of dying. However, the last signs of the approaching death are different. Meyers (1995:48) states that while death is an event, dying is a process. Death is an event, which happens only once while dying is the processual part of it. Dying is a journey towards the impending death. Death is marked by mourning while dying can be marked by suffering, practices. The process of dying may not be universal unlike death. The finality of death for the teams means closing the file after a required number of bereavement and post bereavement visits. The narratives of people who talk about dying and death in their own case are often broken, chaotic in nature filled with long pauses, sobs, wailing or silences (Frank 1995). During the process of dying the patient's explain the sadness over their death on the basis of leaving certain unfinished tasks behind but as death approaches i.e. a few days, hours or minutes before the actual event, the patients are less anxious over the worldly responsibilities. If such thoughts linger till the very last, the teams guide the family for assuring the patient that all her responsibilities/unfinished tasks shall be taken care of in the absence of the dead. Many patients await such an assurance and thence, the permission to leave before they die. These assurances are communicated by a loved one holding hand in the last hours and assuring the patient not to worry about her responsibilities and in the field it is called as the process of 'letting go'.

Maxi, a middle aged nurse cum counsellor, narrates her experiences with many patients over the years where they needed to be assured that things will be taken care of before they could die peacefully, in one such case a man in his late seventies was on his deathbed, the team visited him twice during this period. In the initial visit, they were assured that he would be dying soon but his condition worsened, he was living with his wife and an alcoholic daughter. In the next visit, the team was a little surprised to find him still holding on to life and Maxi decided to take charge of the situation. She sat by his bed side and asked directly what made him stay despite the suffering. He was shedding tears while sharing his concern about his wife being unable to mange funds and the responsibilities of the house all by herself. Before leaving, Maxi shared his concerns with his wife privately. At two in the midnight she received a phone call from the family, the patient said a thank you while Maxi prayed for him. In the bereavement visit, his wife shared that she decided to assure her husband that she would be able to manage without him and he, in return, said that he could leave peacefully.

Many of the caregivers, both the teams and the families, share similar experiences from the field. Early in the process of dying, the patient and the family finds it difficult to communicate irrespective of the fact that the patients can feel the death approaching and the families desire death in certain situations. The teams make this communication easier, especially by asking the last wishes of the patient or encouraging the family members to ask about it. They begin by preparing the families. Everyone knows death would be inevitable yet the palliative care teams make it easier for the patient and the family to acknowledge this and support them in deciding the last decisions, making final calls or farewells, settling issues, burying the hatchet and choosing their funerary wishes, writing wills.

The patient is bed ridden, the wife shares that he has almost stopped eating or drinking. He refuses to take medicine too. The nurse sits with him and feeds him with the porridge prepared by his daughter that has been kept at his bedside. She keeps talking to him in his ears. He very softly asks the nurse to pray for him (his end), the nurse smiles while moving her hand over his head and asks him what makes him think so? He opens his eyes a little and shares that he knows he doesn't have much time but his family is not ready to understand.

Now, nothing much remains in this body. ("*ab is shareer main kuch nahi bacha"*)

In the meantime, the counsellor goes to the kitchen where the wife is preparing tea for the team. Here is an excerpt from the communication between the wife of the patient and her:

C: What do you think? (" *Aapko kya lagta hai?*")

Wife: Weeps and hugs the counsellor.

C: You have to tell him to let go, he is waiting to hear it from you. (" *Unhe jane ke liye kehna hoga, woh apse sun na chahte hai.*")

Both of them stay in a close embrace till the wife regains her composure nodding her head swiftly and wiping off her tears. The counsellor hints me to give her some water. I give her a glass of water and put my arm around her. She says, 'yes, may be this is good for him' ("*haan shayad yahi acha hoga unke liye").* He remained in this condition for more than a month before his death. In the bereavement visit, the family, the wife and the daughters, expressed their gratitude (*"ehsaan"*) sharing that they began to talk about his wishes as well as were ready to allow him to leave. The wife shares,

> 'Last moments were very fulfilling. When someone dear to you leaves it definitely hurts, but all of you helped us to understand his needs, he was waiting for us to be fully prepared before he could leave.'("*Yeh akhiri time acha guzra. Jab koi apna nazdeeki jata hai toh dukh hota hai par aapne sahi samjhaya tha, woh humare bolne ka intezaar kar rahe the khud jaane se pehle.*")

The daughter interrupts,

> Papa asked *ammi* to wake all of us and as we gathered around him and he raised his hand as if saying a bye or may be suggesting that everything was ok. That's it, finished ("*bas khatam*"). *("Papa ne ammi se hume uthane ko kaha, jaise hum saare unke saamne aaye unhone apna haath uthya. Bye kar rahe the ya kehna chah rahe the sab theek hai. Aur bas khatam") (*Begins to sob as the nurse tries to console her by rubbing her shoulder gently.)

This insight from the field illustrates the fact that the mention of death during conversations allowed people to prepare, grieve and detach before the actual event of death. There is a constant shuffling in the needs and desires of the dying and at the moment of death, in many cases days before death occurred, people slipped into unconsciousness and were unable to speak or share anything. Families shared their sense of gratitude to the teams where the deceased could share before slipping into unconsciousness. As a caregiver, mentioned in the Remembrance Day (an annual event held by the organisation to remember the loss of the families and show solidarity in their grief),

> 'I don't know if my mother would have wished something else at the time of her death, after lying in a semi-conscious state in her bed for a month but the team kept visiting us. We were in touch with them for almost two years and the team helped us in discussing about it quite some time ago, even before her health began to deteriorate. She was prepared for it and made sure to explain smallest of things, related to her cremation, her will and even used to ask for dishes she desired to eat.' ("*Mujhe nahi pata ki mataji apne antim samay main kuch aur chahti thi kyunki kareeb ek mahine pehle se hi woh thodi behoshi si halat main thi. Lekin team humare paas aati rahi. Hum inke saath kareeb do saal se jude rahe, aur team ne hume aur mataji ko kaafi pehle se is bare main baat karne ki salaah di thi, unka swasthya bigadne se pehle. Woh (mataji) tyaar thi, hume chhotti-chhotti cheezei samjha di thi aur yeh bhi ki unka daah-sanskar kaise karna hai, woh apni will likh gayi thi yahan tak ki khane ke liye apni pasand ki cheeze bhi banwaya karti thi.*")

Preparing a family is not easy and the team members do it in parts. They provide the information in piecemeal, prod the patient and families to hear their expectations or reactions and take a cue from these interactions before moving any further. Gawande (2014:185) narrates this process as 'breakpoint discussion' among the Swedish doctors.

> "a series of conversations to sort out when they need to switch from fighting for time to fighting for the other things that people value— being with family or travelling or enjoying a chocolate ice cream. Few people have these conversations, and there is a good reason for anyone to dread them. They can unleash difficult emotions."

There are cases where such conversations are taken well but there are exceptions too where this is misunderstood, considered inauspicious too. Dying is not a unilinear trajectory but a mixed bag of random events and the teams steer through by taking calculative risks.

Communication: good death and dignity

Aries (1965) uses the term 'tame death' and before him Kubler Ross (1970) came up with a more temporal concept of 'good death'. The literary definition of good death across cultures has been without suffering, in sleep. The teams frequently use this concept but with a clinical understanding of painless death. The families refer to a 'good death' as *"ache se gaye"* (*acha* is good while *gaye* means to go) implying peacefully. The patients express their understanding of the term 'good death' as their desire to go away without any discomfort and dependency, "*chalte firte*" (which implies 'while still able to move). The good death is also associated with patients' non-dependency for toilet needs, "*tatti-pishab* or latrine-bathroom (both the terms were used by people depending on their educational/class backgrounds) *bistar pe na ho*" that is bed wetting and soiling the sheets. For the families or the informal care givers, a good death implies a 'clean death'. The term 'clean death', as I use it and not the families, is understood as their idea of a body 'without visible afflictions'. Many of the patients desire dying without rotting to death ("*sad-gal"* (to rot) *"kar na jaayein"* (not to go). Rotting to death is associated with the sight of out-growing tumours, erupted tumours leading to non-healing wounds, fungating and smelly wounds, pus oozing wounds, wounds afflicted with maggots, pressure sores and any sight and signs of mutilation on the body. But the families express their remorse by saying it could have been them in place of the patients, no one wants it this way, but what can we do? We can be in their position next ("*aisa to koi nahi chahta, par kya kar skate hai. Hum bhi ho sakte hai kalko.*").

The patients express their fear and shame over tumorous growths and associate it with a bad death. For instance a woman ashamed of the tumorous growth in her cervix protruding out of the vagina shares,

'Dying due to this disease has made my death worthless.' ("*is bimari se marne se toh maut bhi bekar ho gayi*")

Similarly, Ashutosh, an octogenarian living with advanced prostrate cancer, passed away in his sleep. He used to live with his wife and an alcoholic and abusive son. His wife shares that while she thought it to be a good death as he died in his sleep, it was not. The wife, in her late seventies, the sole caregiver who complains about the care work citing her own age and often shares experiences of her bad marriage. She feels that he used her for producing babies and barely cared for her over the years. After his death, when they took out the urinary catheter for bathing the body, there was a bunch of maggots at its mouth inserted inside his bladder. She shares that,

‘he didn’t get a good one, but then he paid for his past deeds.’(“*ache se nahi gaya par apne karam bhi toh yahi katne the*”)

The above instances from the field show that a ‘good death’ is understood by the dying and those close to them in very different ways. For the teams, a good death implies relief from pain as well as other symptomatic discomforts like distressed breathing. In every bereavement visit, they make sure to ask if the patient was pain free at the time of death. Maintaining the hygiene of the patients in their last hours is an absolute must. The teams suggest many caregivers ‘to bathe and shave their patients and make them wear clean clothes’, after which many patients are seen to show the signs of approaching death and die ‘peacefully’. Otherwise, too, in the regular course of care of the patient the teams suggest and insist on keeping the wounds clean and doing fresh dressings.

In the field, a bad death for the dying means no control over erupting tumours, uncontrolled bodily secretions, visible invaders like maggots and the incessant pain but the actual moment of death observes a different understanding despite the prevailing ideas. A homeless man with a large fungating wound in his mouth used to stay in the shelter home of a public hospital situated opposite to the out-patient clinic facility run by the organisation. In his teens he ran away from his house in Delhi and was staying in Mumbai till he became aware of his HIV positive status. He married a girl in Mumbai and was expecting a child when they became aware of their HIV positive status. His wife left him accusing him of giving her ‘AIDS’ and terminated the pregnancy. He came to Delhi in the hope of meeting his family but they refused to accept him. As he began to pull carts in Delhi to make some living, he was diagnosed with oral cancer. It spread fast and he lost half of his face to the engulfing tumour. He decided to stay outside a public cancer hospital and came in touch with the staff members at the out-patient facility. For a few months of his survival, he was able to spend time and share his pain with them. The counsellor used to spend a lot of time with him and had kept his family's contact details with her. He would come for regular dressings. It so happened that he did not show up for two days, the counsellor asked one of the staff to find him. They found him lying unconscious next to the *nullah* outside the hospital. They saw maggots wriggling in his wound. They picked him up and brought him to their clinic with the help of people near the roadside. They cleaned his wound from maggots, shaved him, washed his face and made him drink some water. In an hour, he gained consciousness while gasping heavily. The team was prepared for his death. They called his estranged wife and mother over the phone. The mother assured of coming to see him in his last hours while the wife was very angry and expressed her disinterest in talking to him. When the mother reached the clinic he was in a gasping state desperately trying to breathe. As the counsellor shares, 'he was trying to vigorously throw his body here and there and was shaking his head a lot'. The counsellor once again called the wife and asked her 'to speak only four words; 'I have forgiven you' *("maine aapko maaf kiya")*. She agreed at the behest of the counsellor and the nurse held the phone near to his ears. On hearing her voice, he stopped moving vigorously and the tears streamed down his eyes. Within the next few minutes he took his last breath and his mother took his body for cremation. His siblings didn't attend his funeral. The team found it a satisfactory ending for the patient as well as them. The patient was on the verge of a 'bad death' had it not been for the staff's efforts to look for him he would have died near that *nullah* outside the hospital gate. The next few hours of intervention, assured him some control over his last moments. The process of his dying may not have been dignified but the efforts to make his moment of death a peaceful one were. It is one of the examples of the fluid boundaries of good and bad in the event of death and dying.

The teams try in their limited capacity to make dying comfortable but the families bear a greater onus. For instance, in many cases the families and patients do not have a dignified living. When a caregiver shares her perennial and prolonged hunger while grieving over her husband's recent death,

'my husband was a good man, very honest. We do not have any debt but a regret that today when he passed away I have all the food for myself and yet I am unable to eat it. Since I got married, almost forty years from now, we never had filling meals.'

In my opinion, that is wretched and undignified. As members of a society, their basic needs were never fulfilled. She never expressed her needs for an insufficient meal till her husband was alive or else the team could have helped her with the three month rationing support. Weekly visits assured them of free medicines and other support material like mattress and adult diapers yet there was a huge void. Poverty is seen as a bigger culprit than cancer in the field.

Prema, who lives with her husband and two children aged five and seven, shares that they boil rice and eat them the next morning after soaking them in water. That makes for their dinner as well as the breakfast. For lunch the mother shares the kids get something from the '*langar or bhandara'* (the food feasts organised by people for religious and charitable reasons). The nurse gives her own clothes to this woman who found it difficult to wear synthetic clothes over the small pustules covering the mastectomy.With no basic provisions for food, shelter and clothing many families live without dignity.

In one such visit Chaman, a nineteen-year-old boy with osteosarcoma, is eating lunch, as we enter his house with a small kitchen at the entrance and a 8 x 8 feet room. The counsellor suggests the mother of the nineteen year old patient to pour some clarified butter as that will render him some strength. As the nurse opens her bag for his dressing, the mother goes to the kitchen and sits down on the floor stuffing her mouth with the saree *pallu* so that her son couldn't hear her cry. I follow the counsellor to the kitchen and we sit besides her, she shows the almost empty containers of rice and wheat flour whispering the lack money for basic food so affording fruits, vegetables and 'clarified butter' is impossible. Later, the organisation allots them the food supplies for three months. Usually, the teams put an application for allocation of funds and this is decided after a meeting and took sometime. The teams often fear that in case the patient died before the meeting, the family would be deprived off this assistance. With the allotted funds we buy the least expensive monthly stocks of rice, wheat, oil, pulses, salt and sugar so that we could buy more food supplies in terms of quantity. Once, in our early visits, I ask Chaman if he has any regrets. He shyly confesses the lack of money. An avid cricket fan, he believes Yuvraj Singh, the cricketer, survived because of the money and his ability to go to America. The team tries to talk about the different kinds of cancer, differences in individual prognosis, the good treatment in AIIMS but he does not engage in any more conversations, listens to the team and smiles at us.

Despite making provisions for symptom management in last days, the process of dying lacks dignity if observed within the above contexts. But in the above cases, the families express their satisfaction with the death of the patients. For instance, in case of Chaman, the doctor from the team has seen his latest scan reports and the team begins to prepare the family about patient's death. The boy who is hopeful of being able to walk, after undergoing surgery in which half of his shin bone was replaced with a metallic rod, begins to use crutches. My visit's come to an end and the team keeps updating me about him. He passed away in next six months and I joined the team to meet his mother for a bereavement visit where she narrates his death as a peaceful one.

'He used to ask me not to shed tears after he dies and care for myself. Doctor sahib had told us everything. Chaman told me to sleep well after his death. (Cries inconsolably, regains composure and begins to whimper) He regretted not being able to live so that he could support me given his father has never done that. (One of her son was addicted to drugs (smack) whereas her husband was an alcoholic). Doctor sahib had informed me that he will pass away suddenly ("*Achanak jayega bata diya tha, use bhi pata tha"*). Since morning he was a little passive, lying in his bed. I asked him if he wanted to eat or drink something but he nodded his head in denial. He wasn't speaking much. I went to the kitchen to prepare a glass of "*shikanji"* (nimbu paani or lemonade) for him. My another son called me anxiously, I came with the glass in my hand and he was gone. My son told me he saw the head tilt in one direction. It happened really soon. From getting up and being able to walk, Chaman's expectations reduced to using crutches and being able to sit outside everyday. Gradually, he sensed it was near and would ask me to not cry over the loss. Then he wanted to go while watching TV without any discomfort ("*bina kisi takleef ke, khate peete, TV dekht*e").'

Gawande (2014:259) mentions the minimalist control people seek even in their last days, the ‘trade-offs’ they are ready for in the wake of a nearing end and explains that medical profession often overlooks the scope for such negotiations. His text if compared to my field findings, however, presents a relatively curios intent as well as awareness of rights among the patients in the USA to negotiate the choices in the case of a terminal diagnosis. In case of the patients in the present study, such open negotiations are barely imagined in the hospitals with the doctors, especially if the patients come from poor and less educated backgrounds, but they find it easier to communicate their anxieties with the teams. Often the families and patients share the terminal diagnosis using phrases like, ‘doctors have raised their hands’ which implies they can’t offer anything further (“*doctors ne haath khade kar diye”)*, ‘doctors have lost all the hope’ (*“doctors ne jawab de diya hai”*),‘doctors saying nothing more can be done’ (“*doctors bole ab aur kuch nahi ho sakta”)*. Such reactions devastate the hopes for the individual and the families. In many cases, patients are provided with a deadline too. For instance, Susan (a thirty four year old) is advised to stay in a hospice for two reasons; firstly, her ‘son is very young and her husband can’t stay at home through out the day to care for her, secondly, she has only two months due to the metastasised stomach cancer’. I met her for the first time in the December of 2012 and for the last time in the summer of 2014. She shares that there are moments when she feels she will not be able to sustain for more than a day but fortunately she has sustained. A devout catholic she perceives it a miracle for her son. In addition, she shares her visit to the hospice which made her decided to stay at home and die even if it was going to take two months. She found the place ‘too scary and lacking warmth’. She shares that some of the caregivers informed her of a room in the hospice where they transfer the dying patient so as to avoid stress among others. Hearing about the room, she decided to die in her own home amidst her family members. Her prognosis has been a roller-coaster experience and now she doesn't cry, unlike earlier days, over her pillow fearing death. At times she wishes to show up in front of the doctor who gave her two months. She jokingly says,

> 'Who knows he might die of shock' (Everyone, her aunt and the team members, in her room begins to laugh loudly).

Whose '*Ichcha'* (wish)?

When in pain or bed-ridden, many patients request for an injection or some medicine that can put an end to their misery. The teams handle such requests within their capacities but many of the team members share their confusion over the autonomy of the patient and the inability to keep all sort of situations under control as the disease progressed. Minocha et al. (2011:26) express an understanding of euthanasia within the Indian context and highlight a neo-liberal ideology that stresses upon people's autonomy on their own lives, the role of individuals and an upcoming culture of dignified death or good death. The history of palliative care shows that it emerged in opposition to euthanasia (Clark et al. 2005). On 7th March, 2011 the Supreme Court of India legalised passive euthanasia for people who are either brain dead or are in a permanent vegetative stage (Minocha et al. 2011). Gawande (2014:245) expresses his legitimate concern over the misuse of such rights but fears more the dependence on them as in the case of Dutch population where the palliative care remains under-developed. Norwood (2007) narrates her experiences with the Dutch doctors and the discourse over euthanasia. She explores the discourse and shares her findings in Dutch population that an application for euthanasia provides people a sense of control and only a handful might actually use it. This sense of control is not individual in nature and involves the family members too.

> "In the Netherland, for instance, the system has existed for decades, faced no serious opposition, and significantly grown in use. But the fact that, by 2012, one in thirty-five Dutch people sought assisted suicide at their death is not a measure of success. It is a measure of failure. Our ultimate goal, after all, is not a good death but a good life to the very end" (Gawande 2014:245)

As per Minocha et al. (2011), the western thought lays emphasis on individual autonomy, India is catching up yet the larger population thrives on sustaining through the relationships. In India, a debate on legalising euthanasia keeps emerging. Aruna Shanbaug's case brought it to the forefront and resulted in legalisation of passive euthanasia too. In the field, the situations are difficult. The issue of euthanasia can not entirely be debated by looking into people dying with cancer. People living with other chronic and either life limiting or life threatening ailments, an ageing population, people living with disabilities need care in some or the other form as does someone suffering from flu. The gravity of suffering is enormous, yet I intend to bring attention to a larger social understanding of the issue.

In the field, there are patients who are completely bed-ridden for a year and more as well. They are conscious and fully aware of their lives but never fully in control. The moment some of these patients mention assistance in dying or share their suicidal thoughts, the team members take a note in the file. The teams keep their guard on, counsel the patient but make a special note about such a request and inform the head office in case of a mishap. This is to safeguard themselves, as a counsellor shared. In the regular monthly meetings, the teams are often reminded to take extra care in such cases and immediately report them to the head office. I attended a workshop organised by the organisation in association with another NGO who work to assist suicide callers. This is to bring to the notice that in certain cases, people with cancer contemplate suicide especially as the suffering increases and hence, the teams as well the helpline should stay vigilant.

A paraplegic patient belonging to upper middle class, a man in his early forties was suffering from osteosarcoma of right leg for the last nine years. He used to be ‘impatient and angry all time’, ‘may be because he was a paraplegic’ as the doctor mentioned. After he passed away and I accompanied the team for a bereavement visit to his family, the family expresses their contentment with an end to his miseries and eventually their own ordeal. His wife and old father take deep sighs in the middle of our conversations and keep repeating, ‘whatever happened was good’(“*chalo acha hua*”). The wife shares that he was a constant sight of suffering with a vegetative body and a ‘talking mouth’. The family mentions that he rarely talked ‘sense’ and used to hurl abuses on family members most of the time, he felt that the team ‘should be at his beck and call’. His sister shares,

> ‘He was frustrated with being on bed for the last few years and contemplated suicide and many counselors from the organisation came to help him with his suicidal tendency. Finally he found what he longed for, ‘peace’. Our country neglects the pain of such people; it is more mental than physical.’

Some of the team members perceive euthanasia as a solution to this neglect whereas others brush it off as an inhumane alternative based on their field experience. In his case, some of the team members felt that he was a ‘disturbed personality’. As discussed earlier, during the counseling course, in one of the classes on euthanasia, there was a heated debate on the preciousness of life, the right to live as against to kill. Passive euthanasia, though now legal in India, was frowned upon while three participants supported this practice. Those who supported it were given a situation of famine in an area where no support could have reached. What would you do? Will you go for mercy killing in the dearth of aid? The participants cited the differences in the context but then everyone lost the zeal to argue over it and finally accepted how euthanasia is a malpractice, after the class a few shared their discontent. Outside the classroom, while spending time with different teams during home care visits, the staff members were able to share their opinion more freely on the issues of euthanasia and palliative care.

Counsellors and nurses from different teams confide the difficulties in imagining life in the kind of conditions they witness every day. Doctors do not try to engage much in deeper conversations regarding the issue of euthanasia and often call it ‘unethical’. In one such case, when I remind a doctor about it being legal in other countries she replies, ‘theirs’ is a different culture they are mature societies’. Another doctor states that physician-assisted-suicides has a risk of physicians as the ‘perpetrators’ and ‘no doctor would be ready to bear such a responsibility and therefore, it is easier for the nurse and counsellors to suggest it or talk about it ’. A counsellor adds that some of them discussed it in the office where ‘everyone calls it bad and no one is ready to listen anything related to it’. Another counsellor, ‘blames it on the religious rhetoric of euthanasia preached in the counselling course’. This counsellor criticises the training course and mentions that it was ‘bereft of psychologically sound arguments’. One of them further adds that this one patient who used to live alone in a shack couldn’t move much, was in immense pain and during their visits they would clean her bed pan which used to be by her bedside filled with filth (*gandgi* : the term was used for urinary and faecal discharge) and the houseflies swarming around. The nurse says, ‘we would cover our faces with our scarves’. The teams equate such a life as ‘worse than death’. I ask if the woman in this case ever expressed her desire to death and they get a little uncomfortable and say no. One of them suggests me to read literature on euthanasia to strengthen my research work instead of asking such questions. They are later talking among themselves, as I sit in a corner to silently take notes of their conversation.

> C 1:Euthanasia [*ichcha* (will) *mrityu* (death)] should be an alternative, no? (“*Ichacha mrityu ka option hona chahiye nahi?*”)
>
> C2: It is about our choices, there is no dignity for rights or life and we talk about dignified death. (“*Arrey, apni choice hi nahi hai, life main koi dignity na ho par quality of death ki baat karenge*. “) (everyone laughs)
>
> N 1: despite what we might be trying to provide others. Palliative care is not a panacea *(sanjivani booti”)* (“ *Palliative care sanjivani booti nahi hai, chahe hum logo ko kuch karle”.)*
>
> C1:No one wants to talk about it; our doctors are the laziest of the lot. And everyone goes to the field for the sake of their profession. (“*Arrey koi baat hi nahi karna chahta, humare doctor sabse sust hai. Aur field main sab duty karne jate hain*”)

In the above conversation, the counselors reflect upon the state of lives but understand the choice to die as their own, whereas the nurse reflects from a curative perspective putting her own practice into question. The conversation is, however, not to reflect the discontent of these staff members belonging to different teams but to their reflections emerging from the field.

During my visit to a family from Uttarakhand, the patient used to work as a truck driver when he was diagnosed positive for HIV. Later, he suffered from oesophageal cancer too. His family shares that a night before our visit he tried to jump from the balcony of their small two floor house and his sons forcibly pulled him in. The team talks to him making him ‘understand’ that life is a ‘god’s gift and therefore, one has no right to take it and let the nature’s course prevail’. This case is further shared in the monthly meeting and I find some of the counsellors [‘only’ them given that there were doctors as well as nurses too] smirking in disapproval. Later during the lunch, I ask one of them the reason behind that shrug and smirk. They share it rather collectively stating that the entire premise of God ‘creates a hope based on a false premise’ and a ‘dialogue on euthanasia is necessary’. Another group of counsellors finds this logic to be ‘pseudo-modern (*faltu-modern*)’ and share their experiences where in some cases even the staunchest of the atheists are found to negotiate with the God. Green (2008) in the first chapter of his book shares many works in the death studies suggesting similar findings. The counselors are divided into two groups and are often seen to convince each other with their stance but never allow these differences to hinder their communication with the dying on the basis of a believer-non believer divide. The group begins to discuss the social fabric of India where law is ‘often’ misused in dowry and sexual harassment cases but they are never scraped out while one’s own right to die has been lulled after Aruna Shanbaug’s case[43]. As a counsellor shares, but Shanbaug, who was bed-ridden for 38 years, was not in a position

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[43] For a detailed verdict on euthanasia in case of a petition filed on behalf of Aruna Shanbaug http://indiankanoon.org/doc/235821/

to make choices for herself, neither she was brain dead. The members from different teams share information (many of whom I know) about people who have asked for death. In the field, I find teams counselling the patients contemplating suicide and make provisions to keep them pain-free yet some members share that the miserable living conditions due to physical dependency aggravated by lack of good care in the dearth of resources is a reason enough for a right to choose between life and death. Many teams, on the contrary, share that there have been numerous cases where the team worked on managing symptoms related to pain and other physical discomforts when the patient expressed a desire to live.

I visit Shankar fortnightly for over five months, gradually he and his wife take time to open up with me. It is already over two months, when the team shares with me that he contemplated suicide almost four times. In one such visit, two counsellors visit him instead of the normal protocol of a nurse, doctor and a counsellor. In this session, he was angry with God for making him suffer with the disease and spoke about ending his life. He had a huge cauliflower wound on his leg then which he kept covered with the dressing. Gradually the wound healed completely and the team expressed their surprise. The nurse shared that the doctor always felt that he will die because of this wound. Doctor from the hospital has suggested so many dates but he has defied the deadlines. ("*Hospital main to kitna date de chuka doctor, par yeh sab date paar kar gaya.* ")

Gradually, the team talked him out of it and he shared it with me in his later visits. Shankar expressed his 'little bit' of happiness, now that his wound has healed and morphine worked for him fine, was because of the doctors (in many cases, it was found that patients and their families address everyone in the team as a doctor and sometimes those who accompany them, for instance I, despite introducing myself and my purpose of visit at every visit)[44]. I ask if he still wishes to die, to which he replied with a strong no stating that,

'madam, anyone is bound to think this way in troubled times.(*"mushkil ki ghadi main har koi aisa hi sochega madam"*)

He was not the only one to say so. While some of the team members perceived living conditions and lack of resources as parameters for a poor quality of life, which no doubt were. Such basis cannot be a decisivecriteria for euthanasia till the time we as a state and a society can fulfill the responsibility of better living standards for people in general. It must be recorded here that there were patients who did not complain about their conditions but the team members found them grossly uninhabitable. Howarth and Jeffery (Minocha et al. 2011) lay emphasis of understanding euthanasia on the inter-generational basis instead of a utilitarian logic (as people in a population are of no use after a certain

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[44] During one such visit, one of the patients addressed me as 'doctor sahib' to which I promptly intervened asking her to call me by my name as I am only a student researcher. She smiled and we carried on with our conversation but later during the day the doctor from the team asked my reasons for sharing my identity. I explained it to be an ethical aspect and also if I am not a doctor why should I be thought of as one? Such a perception can later land me in trouble during my further visits, no? The doctor was a little irked telling me that I am not fully aware of the term doctor which implies a ''healer'' for the patients and their families. *"You are healing them even while talking to them, explaining your designation would change nothing…..didn't you see how she was sharing her painful experience of the last hospital visit despite you clearing your position?...This is a wasteful exercise. You should focus on the information she provides you instead of clearing the ground…..you will anyway remain a doctor for 'such' patients…..well our counsellor and nurses are 'doctors' all the time. They (the patients) can easily distinguish between bada doctor (Senior doctor i.e. the actual doctor from the team) , chhota doctor ('Junior doctor' The nurse who gives medicines, does dressing and measures BP), dimaag ka doctor (dimmag ,[Trans. Brain] is spoken here as mind : the counsellor who does mann ki baat (where baat means talk while mann means heart, more like pouring your heart out; acknowledging mind). Language is meant for simplifying communication and not to provide information which is irrelevant. You are not going to harm her by being a researcher so what's the point? "*

age and pose financial burden to the society) which Harmala Gupta in her interview critiques,

> ‘for euthanasia to be the only recourse left in our society so bereft of values based on shirking the weaker and disposable ones seems absolutely ridiculous. Palliative care is to journey the dying and debilitating instead of giving them an injection and do away with them.’

Preparing for the death: Living while dying

The palliative care teams often come in contact with the patients immediately after the diagnosis. Some of the households come in touch after the patient had already undergone a lot of suffering. But beginning from the moment of contact, the teams make efforts to bring relief to the patient. Even if it is for a week before the death, the initial focus is to provide pain control and manage other physical symptoms. It is observed that in cases where the patient usually has very less time, the initial visit often had a cathartic effect. They come up with their unresolved issues seeking a closure for a peaceful death. This section provides an account of people’s understanding of death. In a lot of cases, people begin to fall, loose motor control, unable to visit the loo and sit or squat on the seat, suffer from painful and distressing constipation and the problem of incontinence, find it difficult to swallow food, become completely bed ridden, feel weak and are lethargic, reduced to bones with almost no flesh. Many patients stop eating from mouth much before they die, they are intubated and face dryness of mouth and regularly complain on a sticky mouth (“*muhn chipakta hai*”).

Many households have people waning each day, the sense of decline is visibly perceptible through the vivid imagery of shriveled skin, sunken cheek and eye sockets, frail frames, dissuading pallor, weary smiles and diminishing appetites, incontinence, yet no mentioning of death on the part of the patients is a little strange yet understandable. Who wants to mention something that obliterates the sense of identity and that too in their own case? They are sad, depressed, often unable and sometimes indifferent towards accommodating certain acts of care, for instance the suggestion to consume a nutritious diet. Some cry throughout the day. They are aware yet unwilling to talk about it directly. The statements provide cues to the teams, 'what's the point of eating?' ("*kha pee kar kya karna hai"),* 'now, what's the benefit of consuming so much of medicine' (*"ab itni dwai khane ka kya fayda"*),'why to wear new clothes?' (*"kya karna hai naye kapde pehnkar")* , 'all of them should be happy, that's it' ("*bas yeh sab khush rahe*"). The family members often a father, a mother, a sibling, a child or a spouse are seen hushing up sobs while in the kitchen or another room or faking up busy-ness to hurriedly wipe tears or choke up to an extent that the veins well and lumps in their throat become noticeable, literally as well as figuratively. If someone from the team tries to mention 'death', it results in inconsolable outbursts. But that mention is never direct, even on the part of team members, it is brought up indirectly. Yet it is communicated. The teams feel the relevance of communicating death through language that helps in preparing the patient and the families.

In their last days, many patients linger on for weeks together. In the case of Kirin, whose daughter is to get married in a month and a half, she has already begun to mention death. It is communicated through actions where when she asks the team to take back the wheelchair, the team assures her that it shall be taken soon. No one is mentioning it clearly, yet subtly they indicate it to each other. While the team tries to provide them with a vegetable cart as a means of rehabilitation, the application procedure is long. Nevertheless, she shares her concerns that she is aware of the fact that if she passes away before the acceptance of the application, her family would be left to fend off by themselves. She vaguely expresses her desire to attend her daughter's marriage. But as her daughter's marriage approaches near, the desire to attend the marriage grows, not only for her but the team begins to wish for 'some more time'. As a member from the team shares almost every day, 'she should die either today or after the wedding only.' As a week remains to the wedding, the nurse begins to pray in the evening for Kirin till her daughter's wedding. As the visits continue, she keeps on expressing the importance of each day and mentions the uncertainty of her hopes. The doctor says, 'we will manage the pain, rest is up to her destiny and the God'. She is able to be a part of the celebrations and dies away a week later. All through she has been in immense pain and people from her jhuggi cluster complain of sleepless nights due to her screams while pitying her condition.

The moment of death as closure

Chunni, a twenty three year old girl with a two year old daughter is in her last hours. While she is surrounded by a lot of village women, her father waits outside her room anxiously to hear that last breath. He has already mentioned to us ' there's not much time' ("*zyada time nahi hai*"). The counsellor, a male, stays outside and begins to talk to the father. When we reach inside she is gasping condition with her mouth open. She is emaciated and lying on her bed with a naked bulbous leg protruding from the cloth covering her modesty. Looking at the huge tumorous growth, the nurse whispers that the leg could burst with the prick of a pin. As we reach her bedside, the nurse calls her name and she begins to throw her arms in the air faintly screaming with all the strength in her body, ‘save me…save me..cut off my leg…doctor sahib save me’ (“ *sister bacha lo, sister bachalo, tang kaat do, bacahlo doctor saab*”). The nurse places her hand on Chunni’s head to comfort her and asks the women surrounding her to spread out and allow some fresh air for her to breathe. There is utter chaos around the patient, the women with their heads in veil and wailing loudly and some assure her that nothing will happen to her. In the meantime, the counsellor calls me outside and asks me to tell the nurse that the father will be coming. Later, I go inside and whisper in the nurse’s ears who requests only one women to stand near her and asks rest of them to gather on one side of her bed as the father is coming. The women cover her bare disproportionate legs and her father is called inside. He and her mother assure her that her two and a half year old daughter shall be taken care of by them while the child is seen running around the house playing with other children. The nurse puts a morphine tablet below her tongue and hints me to make a move. As we move out, the team explains that she doesn’t have much time and since it is our first visit and we still have to visit a lot many patients. Had she passed away in our presence it would be difficult to leave the family and visit rest of the patients. We have hardly covered a distance of three hundred meters and the phone rings informing us of Munni’s death. The father can be heard wailing and he shares that she is no more, ‘she went away’ (“*chali gayi*”).

The process of dying created a specter for the others i.e. family, friends, strangers, neighbours who witnessed her dying but it held different meanings for different people. When we were still at her home, I came out of the room to join the male counsellor who was talking to the inconsolable parents. I see that he is telling them not to take her to the hospital, her end is near and they have to be strong. The father wipes his tears with the cuffs of his shirt and shares that he did all he could to save her, admitted her to Rohtak medical college where doctors had made all the arrangements to amputate her leg but she was scared and in the last moments before they were to take her to the operation theatre she pleaded him to take her home. He further shares that she did not want to live without a leg and today since morning while trying to catch some breath she has been requesting for an amputation in a faint voice and expressing her desire to live. They came in contact with the organisation a few weeks ago and they had expressed pain control as the foremost concern. The team expresses their lack of adequate communication regarding death for the reasons that in the earlier visits the focus remained on providing symptomatic relief, the doctor was still adjusting the morphine dosages while the family was interested in insisting upon counselling for the leg amputation despite teams efforts to make them understand that it was too late due to metastasis. The mother sobs and whimpers softly that she understood that the team meant there was no time to pursue cure but it was difficult for them as parents to see their youngest child die in front of them. The counsellor adds that the only task at hand was to alleviate her pain, keep a check on bed sores and put her on a urinary catheter while the family gave her constant assurances about her two year old. The father nods his head and said that the family understood that there was not much hope but it is difficult for the patient to accept it.

> ‘Since childhood she has been a stubborn girl. We took her for amputation, she refused. Now she is crying for help. This is her destiny and so is ours.’ (begins to weep when the counsellor hugs him) (*“bachpan se ziddi thi, le gaye the taang*

> *katwane mana karke bhaag aayi hospital se, sab tyar tha. Ab rowe hai, iska mukkadar ji aur humara.”*).

Chunni didn’t have a sense of closure till the end.

On the contrary in the case of another nineteen year old, with Ewing’s Sarcoma on his shoulder, this sense of closure came with the increasing pain and breathing discomfort. When we visited him he was sitting with the support of two of his siblings. Unable to speak much, he had his head buried in his hands. The nurse asked him to lie down and sleep, he waved his hand swiftly. His mother said he hadn’t slept for three days in a supine position. He was consuming morphine and was dizzy yet whenever he lied down he felt severe breathlessness. His cousins and siblings were sitting in turns to support him from both sides so that he didn’t fall. He died a day after our visit. This had been team’s third visit only. As the team visited the bereaving mother, she lamented,

> ‘he told his father that he will be able to sleep. He was telling us for the last five nights that death would be better, he desired sleep. (Pauses for sometime, wipes her face with her saree and then wails) He was the eldest, when he died we were devastated yet content. My child slept, finally.’(“*Raat main ape papa ko bola ab so sakega. Woh pichli paanch raat se keh raha tha, sona chahta hu, mar jaun toh bhi acha hai.* (Pauses for some time, wipes her face with her saree and then wails) *Sabse bada tha, jab gaya toh dukh tha par tassali bhi, mera bacha so gaya*”)

In the above case, unable to witness the death or interact with the boy in his last hours, the sense of closure is understood through the mother’s narrative. Kellehear (2015:9) is skeptical of such accounts of dying. I on the contrary find it to be possibly the closest picture possible.

> "To gain a reliable picture of dying staying close to accounts of dying from the dying themselves is essential. If we stray from the dying person's account, we cross quickly into the more unreliable, sometimes confusing, outlook of caregivers, onlookers, rescuers, and the invariably disappointed observers of dying."

In addition, a mother's narrative, who was the primary care giver, demonstrates her own understanding of her son's dying that may help her in coming to terms with the loss. The boy experienced immense distress and many patients like him went through similar comforting before death. In certain cases, the distress was cyclical after bouts of respite. The process of dying not only involves negotiation on the part of the dying but prepares the families to witness the anxieties and negotiate their own loss at the event of death.

Understanding the notion and experiences of death and dying in a hospice

Giddens (1991:156) argues that the modern institutions like hospitals, jails and asylums have all contributed to sequestration of experience. For Foucault these were the systems of control and were meant to keep the marginalised in a population at bay. The literature on hospices shares the common perception of them as death houses. But it is important to understand how those who stay in the hospices perceive them. In the context of patients who are suggested by the teams to visit the hospice in Delhi, the idea was to receive proper care either for a few days or in their last days. The gross living conditions, neglect from the family, or absence of any care provider were main reasons, for which the teams asked the patient to be shifted to the hospice. In some cases, the neglect was intentional while in some circumstantial too. As in the case of, Mahsoon. We often visit him while he sits alone listening to the radio playing on his phone. The summer is unbearable due to the heat whereas winters are difficult given his constantly leaking infection. In one such visit, the team suggests his wife to take him to the hospice for a few days. The sheer distance and thought of commuting for so long puts her down. His brother stays with them and finance is not much of a problem. After much coaxing, they decide to go there. After a month he passed away at home and thanked the team for his hospice stay which was 'very pleasant given his wound was regularly taken care of and he was provided timely healthy meals including maggi noodles.'

Another patient kept begging till last to be taken somewhere he could be cared in a much better way, his family did not comply with his wish despite the suggestions for a few days stay at the hospice. They shared their fear for societal blame for being unable to care for their own family members and leaving them at a place to die and their reputation("*izzat*"). They understood that the paucity of resources made his last days difficult yet they wanted to try everything they possibly could. During the bereavement visits, families share the way the death occurred (a good death or a bad death according to them) and often the biggest regret for families of the dying was about the place of death (if the patient died outside the house), if the patient was in pain, if the body remains clean and without wounds, cancerous or pressure sores (the latter is a sign of poor care as per the formal care providers). In majority of the cases, patients want to die at home. The teams make families aware of the impending death and assisted them in managing the dying till the last hours. This comprises of making families aware of the symptoms of the dying patient. Still, when patients died outside the home, either on their way to the hospital or in the hospital, the families had a strong sense of regret. Death is never observed as bad but there are efforts to avoid a bad death. In case of the homeless patients or patients deserted by their families or even with patients unable to receive dignified care at the hands of their families, the team zealously tried to feed them, clean them, make them maggots free in case they were inflicted, bring fresh and clean clothes to cover them. Many of the patients died within a few hours after the procedure and the team members used to express their satisfaction of being able to avoid a bad death or a death with no dignity.

Also, in case of patients who can 'afford' good care, the hospice is never suggested. During my visit to the hospice, I met a patient, an old man of sixty nine who looked much older, suffering from oesophageal cancer. He had run away from his family in his youth and worked as a door to door salesman. He did not get married and had no one to take care for him. A community nursing officer from the organisation found him during his field visits and brought him to the hospice. He had been staying there for over six months and expressed his astonishment and joy over his improved condition. He could not speak and used to convey himself by writing on paper. He shared his 'contentment of dying with people around and being cared for.'

In the case of Susan, who stays at a posh residential colony at South Delhi, when doctors suggest her a hospice stay. She visits the place and shares with dismay that she could only see 'dying people, frail and tubes to take feed and urinate' *("Marne wala, kamzor log hai, tube se khilana pilana, even bathroom").* She feels she would soon die at such a place and decides to stay with her family consisting of her husband and a fourteen year old son. Death was hidden but she is not scared and wants to die in the open in front of her husband, son and other family members.

During the study, the role of the palliative care teams in the process of dying is not about preparing people for death instead it is about understanding the priorities during debilities, something we face otherwise in our lives during injuries, sickness and diseases as well. But where does this understanding come from? People in distress stop looking beyond the immediacies and often the supportive care teams, their immediate networks of friends, family, neighbours and relatives begin to render support in their own capacities. The teams, a professionally trained group of palliative care experts, are aware of such needs and the patients and their immediate family caregivers narrated their exasperation with hospitals, doctors and nurses who could never reflect upon such exigencies as there was no time and may be no expertise. This chapter shared the priorities which emerged in the process of dying. The nature of theses priorities is not as much about survival but so much with enabling wellbeing, and still being able to have a certain amount of control even in the wake of declining health. Often many of the wishes are considered inappropriate within a family, by the patient or even by the teams. This section engages in exploring the fervent immoralities in the field that are perceived to befoul death.

Sex: A sinful desire, a stigmatised communion

In the field, the women team members, the nurses and the counsellors, would often whisper in my ears about intimacy issues in one or the other family. The spousal equations in many cases relied on allowing or refusing sexual intimacy. Many male patients indirectly expressed their desire and the neglect at the hands of their wives.

Young or middle aged or old, they would share their rejection with teary eyes or with anger. In case of patients with open wounds, tubes and bags attached to their body the sexual intimacy was deeply hampered. Mahsoon's wife refused to touch him. Similarly, Ram Prasad who was in his late fifties stopped consuming his medicines and was angry when in the subsequent visit counsellor came to know about the discord between him and his wife. The patients often cried over the perceived stigma. In some cases, instead of crying they proposed depraved alternatives to the team members too. Women patients were subjected to much poor treatment. A few women patients were unable to refuse and would conceive while undergoing treatment. Some complained forced and unnatural sex. Often doctors advised abortions. The team members guided them where to undergo the procedure. They would undergo abortions, suffer from blood loss, delay subsequent treatment options and resume their lives again. Jimu and Kavita underwent three abortions each. Jimu had CML (Chronic myeloid leukaemia) and her medicine, Glivec, could potentially harm the unborn foetus. In addition, with every abortion she suffered from severe anaemia and I decided to provide her iron tablets for sometime. Kavita had three girls, she was only twenty three and had third stage brain tumour. Her husband desired a son, leading to three abortions.

In another case, a women with cervical cancer was thrown out of the house and replaced with a new partner. The team would visit the patient outside the house where she took shelter. The team was able to counsel the new partner who cared for her till her death.

Age, death and beauty

In the out-patient facility, Dilip, the twelve year old on being asked if he is aware of his condition, begins to speak softly. He hails from a village in district Almora, Uttarakhand he appeared lost, silent and disinterested. I am pursuing the counselling course and this is a field day, so I am at the east Delhi out patient facility. As I sit besides him, I decide to strike a conversation. His age helps me overcome my own nervousness.

Me: Do you know what's the problem with your leg?

D: Cancer.

Me: How do you know?

D: Seen my reports and I am coming to this hospital second time after a year and it is a cancer hospital. It's written everywhere.

Me: Can you tell me more? From the time you came to know about it?

D: I was hurt while playing soccer. I had a surgery. Then I was fine. But a few months ago my leg started hurting again when I kicked a football. I used to play soccer, do gymnastics with hoola hoops in my school.

Me: And now?

D: now I don't do it. Doctor's say cancer is everywhere. (Moves his hand all over his body.) Earlier I looked healthy. (He is reduced to bones with visible knot like protrusions over one of his eyebrows, arms)

Me: Are your parents aware that you know this?

D: My parents think I do not know that I have less days. They have been crying all the time since their last meeting with the doctor, they are crying now also (hints towards the curtain)…I can see them. I have an elder sister who is mentally weak which makes them more sad. Who will care for them when they grow old?

A little stumped with his perspicuity, I interrupt with a 'hmm' tapping at the colour box and a blank sheet he is holding and ask if he likes to draw. He responds in affirmation and adds that he ‘spends his time at home watching his friends play outside’. They call him many a times but his parents keep telling them that he is ‘very sick’. Now he feels that ‘in some days even his friends will come to know that his parents are speaking the truth’. It is getting a little awkward with he trying to sneak at his parents as I attempt to probe him. He answers me but keeps looking at the other side, I ask if he is scared. He replies with a no by silently shaking his head and keeps staring at his parents from behind the curtain. The parents are weeping inconsolably with tears washing their face, visibly shaken while trying not to make any noise fearing he might hear them.

> After the family leaves the clinic, everyone begins to talk about the ‘young’ boy and the ‘sad fate’. A year into the fieldwork, as I visit the clinic again, the staff shares that the ‘young’ boy did not return.

The teams perceive the terminal prognosis among children as the saddest part of their jobs. As a senior nurse shares, that in case of the dying children ‘it’s more about the sorrow of the parents’. Another counsellor shares that in her experience bereaving parents of young children have a difficult time to overcome the grief and having another baby often helps if the parents are still reproductively active otherwise they are barely able to overcome the loss in their lifetimes. I was unable to meet any family. The organisation largely caters to the adult patients and in the field, I was able to regularly visit only four stable children. I never met the fathers and was able to interact with the mothers only who reflected upon the difficult times during the treatment and responded; ‘now it’s ok’.

In his final days, Ramchander an old man of seventy nine with a cancerous gall bladder shared that life had been a pleasant journey for him.

> ‘And everyone, each of us, goes away. Why fear death? Cancer at this age is not very perplexing, especially if luckily there is no sign of pain. Cancer is only one of reasons (“*bahana”*) for death. Body is a machine which with each of its part having an expiry date. Some people die of heart failure while others due to problems like kidney failure, diabetes, jaundice and what not. People die of dengue too. But this disease prolongs the suffering, a lot of pain and visible signs of a mutilated body, no one wants to die an ugly death *(“badsurat maut”)*. I only want a good death, my body shouldn’t be afflicted with worms (maggots) *(“keede nahi padne chahiye bas”)*.’

The team was very happy with his outlook and the counsellor often introduced him as one of the fellow counsellors. Once the counsellor told him that they come to hear him as they find his words very inspiring. Ramchander, however, is a perceptive man, as he got to know about my research work he told me that his understanding of death comes from the fact that he has finished his ‘worldly duties and fulfilled all commitments’.

> ‘Accepting that loss can hurt, it hurts more when it is an unaccomplished life be it with severed relations or familial ties or at a young age, latter being more hurtful. The worst experience for a parent is to observe their child’s death. During my hospital visits, I have so often seen kids with no hair and parents in despair (pauses for sometime) our lives (of older people) are finished while there’s were yet to begin.’

During most of my visits, many times adult patients came up with this understanding that if young children can die untimely, their own death is taking its natural course. It is seen as a means to justify their end. In many such cases, this understanding acts as the consolation. And in cases where this understanding could not arrive by itself, the counsellors were forthcoming in sharing it. Whenever the adult patients were seen worrying over, ‘why me?’ They would be asked how they saw the children living with cancer. In many cases, patients responded by saying that,

> ‘it is only a disease, anyone can have it. Anyone can get it. Even the innocent kids who suffer from cancer, what about very many women and children who are not addicted to tobacco and alcohol. It is all destiny.’

Dying and Dignity

Meyers (1995) makes a clear distinction between death with dignity and dying with dignity, he argues for clarity on the concept of dignity too and brings up the Kantian explanation for dignity as per which ‘human dignity is grounded on the human capacity for practical reason, especially the capacity for moral deliberation’ (ibid.47). He distinguishes the concept of death and dignity and brings up the differences between dying with dignity or death with dignity. Also, Kubler Ross’s (1970) ‘five stage’ model also known as DABDA; denial, acceptance, bargaining, depression, acceptance is frequently used in the west by the health practitioners as a essential subscription in the case of terminally ill. Green (2008) finds it too simple to fit in the contemporary western illustration of death it takes a long time before death happens but finds a lot of doctors using it as a standard prescription. Kubler Ross did not complicate these stages and clearly mentioned the flexible nature of events even if there were early signs of closure. We, in our country, do not have dominant debates or discussions over care, dying and types of death (Minocha et al. 2007) and the activists contest for a space over these issues are barely able to garner attention, the entire populace relies either on privatised care, NGOs, and otherwise the sole major source for supporting care and dying: the families.

However, there were patients who are bed ridden, beaten by the caregivers, left unclean for long hours, denied food and even pain relieving medicines like morphine. As discussed in earlier chapters, with patients lying in their excreta, trying to save themselves from rodent bites, being unable to eat or drink due to family neglect and being outcast due to infestation of maggots in their wounds, in their last days the process of dying is painful and bereft of dignity. With the organisational interventions, they are able to find momentary relief per day a week or biweekly but largely such individuals were on their own. While the some of the team members argue for euthanasia by observing their living conditions, these individuals do not subscribe to the conditions eligible for euthanasia. The idea of dignified death or what is also referred to as the 'quality of death' is desperately pursued by the team members. Dying on the other hand required moderating domestic as wells intimate issues, with more involvement on the part of the patients and the families, where the team members could provide a limited yet meaningful assistance through constant communication, procuring and providing required medical assistance and in many cases through rehabilitation programs of providing ration for three months as well as means of sustenance. Accepting death is difficult and easy depending on the adaptations and reconciliations during the process of dying, for those who were fortunate to fight against time. The negotiations at the moment of death are never about the paucity of resources or living conditions but more about intangible aspects like emotional farewells and unfulfilled expectations or may be nothing.

Dying, thus, involves a whole set of adjustments to the vacillating prognosis and makes people see through this transformation to acknowledge and understand the stakes. The palliative care teams act as the whistleblowers preparing the individuals and their families to identify their roles and responsibilities in the event of death as well as subtly enabling them to recognise their agency. The field is a baffling specter of amalgamations, meanings of good and bad are too subjectiveand fluid with no ideal version of dying. The medical framework or even a palliative care framework understands death and dying from a particular stance whereas an alternate understanding refutes such single idealized version yet it universally highlights the ability or inability to choose as a common ground to understand the moribund lives. Hospices are seen an alternative for resource poor families lacking care. But patients have shared their satisfaction in their last days in hospice space. Many of the patients returned from the hospice to die at home too. Dying is about multiple negotiations and working towards an ending, coming to terms with the physical changes and the emergent responsibilities to care for the bodies as well as mediating the social and emotional transitions. The home based palliative care provides a sense of support in the crisis. For many families, it acts as a source of medicinal supplies and other rehabilitation options too. But most importantly, patients and families get the opportunity to do so much talking with the people working in health care. The conversations are enabling, not as some sort of external encouragement only but more importantly to take informed decisions, to negotiate your inner conflicts or talk about them. As a counsellor shares,

> ‘We do not know anything, not even the doctors and nurses. Everyone is working as per the organisation guidelines aware of the patient diagnosis. That’s it. It is the

> people who are making us work, they know their concerns, fears, anxieties and when they share them with us it is not to seek a validation, they would have validated them in our absence too. But having us as a support gives them more confidence to make informed choices. They know if they will falter, they have us. Even we can falter, no?'

The plans may or may not work. Yet the effort that goes into planning is empowering. It allows people to choose, even if it is not their first choice. For as Gawande (2014:252) says,

> "Endings matter, not just for the person, even more for those left behind".

5. Reflections on cancer and the related casualties: Towards an Ending

I do not intend to call it a conclusion but an epilogue for the reason I wish to write the ending as a story of the last but the foremost protagonist of this thesis. The preceding chapters were about the organisation, the care practices and the process of dying. What unites them? The disease of cancer. The exercise of writing a thesis required translating experience into writing witness sufferings every day, getting to know people witnessing the endings and then coming to know about their demise, and meeting the bereaved families. The challenge in this case was personal and well as technical. The vagaries of the field and the technicalities of meshing it up into an academically oriented content. Ethnographic research writings are as much a personal endeavour as they are the basic requirements for a lot of us situated at different positions within academia. Ideally as well as academically, my position as a doctoral student working towards a thesis based on an ethnographic understanding of palliative care forms a crisp personal introduction. But the research work becomes a personal point of transition in many ways which demand an aware separation between the academic pursuit and personal meandering. It is about witnessing people of my age or younger undergoing chemotherapy and radiation, lying in their death beds struggling through pain and uncontrollable suffering. Their families shattered over the loss, running under huge debts and greeting us with smiles amidst the struggles. In my initial visits, the young patients smiled and sounded hopeful but as I proceeded towards an end in the field I bore witness to their young deaths. While I was on my way to end a fieldwork, their lives also came to an end. This must not be seen as an emotional outburst of field experiences as I write this conclusion much later. But my politics somewhere shrouds the emotional for the reasons that I feel I have been given enough time by the university system to overcome the field hangover at least in its spatial and temporal sense of existence. These two years have been spent in listening to the audio recordings of some of the patients and their family members, going through those field notes, re-reading the field diary and the closest of them all- memory or the head notes as mentioned earlier. Meanwhile, many of the families would call, someone wanted me to be a *rakhi*[45]-sister and while the others wanted to know if I would revisit them or at least once before the patient dies. Many of the team members still keep in touch through Facebook or phone calls. This paraphernalia is a constant reminder as well as a stark reality of the responsibility which brings an overwhelming sense of responsibility and scare. What kind of writing does justice to so many lives who have contributed their time to feed this research? Therefore, I intend to make these memories a part of this thesis. The basic reason for such an inclusion is the fact that the personal is never detached. After leaving the field, it was difficult to begin writing. Writing individual experiences wasn't a problem, but how to shape them into a cogent argument, a body of

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[45] *Rakshabandhan* is a festival where sisters tie a thread, known as rakhi, on the wrists of their brothers. One of the families insisted me on tying a rakhi to the patient's husband who had lost his younger sister. They used to call me sending personal invites to attend various functions at their home or attend festivals. They expressed this desire to the team members too and we had to withdraw for multiple reasons. Firstly, it would have been unethical to make a false promise by tying the rakhi, next it would have not been feasible to commit to this family for a long term relationship as they expected. In addition, the financial condition of the family was bad and the team shared that they insisted on surprising me with gifts often asking about the favourite colour or print of cloth. The husband asked me if I would come once before his wife passes away as she is left with a few years. She was a patient of CML and was in advanced stage. She was consuming Imatinib under the name of Gleevec which is known to increase the survival rate by five to six years and the family including the patient were assured for a longer survival due to a different kind of cancer and the efficacy of drug in comparison to other patients from their locality who had passed away over the years while she was still 'absolutely fit'.I received the last phone call in December 2015 from them.

work within the academics. Understanding the contestation between the results from a fieldwork, the process of ethnographic writing, and the emergent social theory as well as reading ethnographic accounts is an ongoing task for any researcher but to bring meaning to the now-routine humdrum was unthinkably challenging as one experienced it through the ‘first fieldwork’ (Faubion and Marcus 2009). The tradition of writing in anthropology has evolved over the years. From ‘once the benchmark’ macro theories proposed by E B Tylor, Alfred Kroeber, Radcliffe Brown and Levi Strauss to the more sustainable propositions on fieldwork and emergent writing by Franz Boas, Bronislaw K. Malinowski, Margaret Mead have witnessed a string of furores at the hands of interpretivist school and the famous reflexive turn. Yet, the quest has been to improve the skill of ethnography. Historically, the discipline has been fighting its own demons precisely for the reasons of shouldering a responsibility to present the voice of ‘the other’ which in the contemporary times has bearings on ‘our’ when the forces of modernisation have diminished the previous basis of differentiating the populace yet raised newer definitions and distinctions. But anthropologists face a difficult task at hand as it requires keeping up with the pace of the ever evolving social values and perpetually grapple with modalities of writing and moral dilemmas. When anthropologists like Marcus and Faubion (2009) write about the evolution of fieldwork since the reflexive turn and cite the unavailability of hands-on training in how to do fieldwork, carry out a participant observation or the art of ethnography for the naive researchers, it reflects the pithy nature of the task at hand. As much an infirmity, this has turned out to be a much needed appropriation or how else shall we be aware of our own mobile histories and grapple with the ever changing surroundings. Can anthropology really propose a word by word prescription for conducting fieldworks or writing ethnography? I perceive no, it can on the other hand demonstrate by elaborating upon the challenges of doing it, exposing the failures and being kind to the neophytes. Faubion and Marcus (2009) have compiled an array of articles written by authors on the experiences emerging from their 'first fieldworks' that is aptly titled 'Field-work is not what it used to be'. The authors have hinted towards their dilemma of returning from the field and grappling with writing and come out of the field hangover. The initial drafts came out as experiential accounts of three different groups; the patients, the families and the caregivers. But this division later appeared to be too lame for the reason that such a segregated analysis disrupted the flow of narratives which were dialogic in nature. The present version on the contrary was based on the four key themes emerging from the data, namely, the organisation of palliative care in the field, care and its conceptualisation, dying as a different form of social life and a conclusive account of observed perceptions from these three accounts and an epilogue based on the core of this inquiry- cancer.

We as humans have been a witness to evolution from foragers to food cultivators. With industrial advancement, our share over the planet has increased. The average age has increased and so has other travesties of life. The increasing population, newly emerging infectious diseases and progression in the non-communicable diseases is tied at the hip with environmental concerns, state policies promoting better livings choices and creating the tragic living conditions all at the same time. The history of cancer shows our long association with the disease. When I was working on the synopsis trying to develop an understanding of multifarious issues related to palliative care for the cancer patients, the literature provided a detailed account within the Indian context elaborating upon the services provided to the patient, the model suitability with respect to the regional needs of a particular population, the role of morphine and pain control, the technical aspects related to delivery of care. The subscription to Indian Journal of Palliative Care (IJPC) and Pallium India newsletters were two key sources to read about personal experiences of patients, families, nurses and the doctors within the Indian context. A five day experience in the field and mostly the academic literature with western references on cancer, dying and the care was all I had to keep up the fuel for reading and writing. I came across Sontag's (1990), originally published in 1978 in a book form) account of cancer based on her personal journey through the disease. It made more sense than my earlier half-hearted attempt at reading it for I found it too distant from the actual description of the disease and the related quandaries. It critiques the social, literary and popular ways of metaphoring an illness. It is an account of the modern diseases historically known as the disease of consumption (tuberculosis), the disease of the black bile (cancer) with a newly added section on AIDS and its associated metaphors. Her book is not a descriptive account of the illness per se; instead it has much to do with the metaphors used for illnesses in the everyday lives either through the interactions within the personal networks or through popular culture, that is, the neighbourhood and the institutional domains like hospitals or through watching films, reading poetry and novels. She chooses to write about tuberculosis and cancer, as at different times in our history of fighting for treatment and cures these two diseases have unabashedly scared and scarred the human existence. The author analyses the processes and concludes that these diseases have led to untimely wretched deaths while ascribing a romantic character to their own existence.

Later, while looking for secondary literature on cancer, I came across a non-fictional account of cancer sub-titled as ‘the biography of cancer’. Mukherjee (2011), the author of this non-fiction, writes a lucid history of cancer and digs deep into the fears of human civilisation. This is a chronologically written story of the fear of contracting the disease of the black bile (which later came to be known as cancer), the generations of pumping funds into researching the panacea, the quest for survival, the stories of bodies undergoing painful surgeries and hopefully consuming the toxic chemical concoctions. But the thrill of reading this winner of the Pulitzer for non fiction 2011 lies is the way it has been written. It could easily have fallen flat as a narrative of technical facts and discoveries, damages and triumphs in the field of human knowledge. Instead it turned out to be a flowing narrative of the victories and the death in the face of cancer. Reading it in my second year of the doctoral research made me aware of cancer and related issues. No account is complete in itself, yet this was the very first holistic reference to understand the social history of cancer.

Jain (2013) writes ethnography of cancer exploring the uncertainties and employs them as the structuring principle to look for ways to understand and study cancer anthropologically in American culture. The author is of the opinion that cancer means different things to different people, for instance a doctor sees it in terms of proliferation of cells, while in pathology labs or during screenings it is understood in a completely different way. The multiplicity of meanings of cancer renders it a puzzling character. This can be same for other chronic life-limiting ailments. However, what distinguishes cancer, as per her, is its social history and its social understanding contingent upon notions of aesthetics, stigma, negotiations with physical identities. She links this microcosmic understanding of cancer to the larger agencies of state, media, industries manufacturing cigarettes, liquor, pesticides, medicines and cosmetics. Jain (2013)[46] in her work negotiates with these meanings from two positions, ‘as a patient and as an ethnographer, an objective analyst of social forces’.

The discussed texts throw light on the human curiosity of exploring the causes of cancer as well as share its impact on the human societies. With the uncertain nature of its cause and treatment, it has been imputed with different meanings. This epilogue draws its conceptual understanding from the above three texts which I use to explore the meanings of cancer as perceived in the everyday lives of people living with it/ through it/ finally without it (though I am a little bewildered if there is ever a finality in a complete sense of the term to the possibilities of relapse or a re-emergence but presently, I do not have either the knowledge nor the interest to pursue it) and those caring for them. I intend to reflect upon this routine understanding of cancer. This understanding formed the basis of care practices and the experience of dying. Reflecting upon a social understanding of cancer is imperative for the reasons that it is one of the key protagonists of the thesis and the basis of this exploration; the beginning and allegorical ending of the thesis.

Cancer as a metaphor

Sontag (1971: 86) challenges the metaphorical construction of cancer and critiques the mythical language of treatment while hoping for a ‘morally permissible use of cancer as a metaphor’.

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[46] http://www.publicbooks.org/nonfiction/cancers-poison-gift

> “Our views about cancer, and the metaphors we have imposed on it, are so much a vehicle for the large insufficiencies of this culture: for our shallow attitude toward death, for our anxieties about our feeling, for our reckless improvident responses to our real “problems of growth”, for our inability to construct an advanced industrial society that properly regulates consumption, and for our justified fears of the increasingly violent course of history.” (ibid. 87)

Relatively forty years later Mukherjee (2011) presents similar military metaphors in his critique of the contemporary usages like ‘war on cancer’ and the victory over it. He carries out a ‘thought experiment’ seeking a ‘redefinition of victory’ (ibid. 465) by analysing the case of Atossa, the Persian queen who allegedly lived with breast cancer in 500BC, and concludes his work by presenting a chronological account of the scientific developments in the case of cancer treatment. He makes Atossa travel in time for the last 4500 years with the same cancer and observes her journey. It begins backward in 2500 BC with a name for the disease but no treatment. In her own court in 500 BC, she undergoes a primitive mastectomy performed by a Greek slave. Some two hundred years later, the tumour is named as a *Karkinos* by Hippocrates. Galen by 168 AD postulates the cause— ‘a systemic overdose of black bile’ (ibid. 463). For the next thousand years, the tumour keeps growing. In medieval times, the surgeons try to weed it out by cutting it off whereas new remedies like ‘frog blood, lead plates, goat dung, crab paste’, chemicals and holy concoctions emerge as treatment alternatives. A clinic in London of 1778 witnesses stage wise assessment of the cancer and the 19th century presents Atossa with a new paradigm in surgery, a radical mastectomy. At the onset of 20th century, radiation oncology emerges as the newest antidote and by the 50s’ surgeons begin to combine the knowledge and expertise of surgery and radiology. The 1970s' marks the advent of combination chemotherapy followed by hormonal therapy and targeted therapy which further leads to an addition of thirty to forty years in her rate of survival when compared to her chances in 500 BC. By the early nineties, she acquires the power of genome sequencing enabling her to get rid of her breasts even before the tumour hits them, her daughters can be tested, too, enabling them as well to choose breast removal even before the lump turns into a tumour. Mukherjee moves further into 2050 and perceives Atossa to be in a position where she will live on drug therapy through her entire life but the role of these drugs would be to halt mutations and inhibit the pathways all through her life course. He lauds the progress but brings forth the case of other cancers where the rate of survival has minimally or marginally changed over the same span except for cases of CML (Chronic myelogenous leukemia) or Hodgkin's Lymphoma where survival rate has increased by thirty to forty years. In addition, if her breast cancer tests negative for a hormonal compatibility (referred to as testing negative for estrogen reception, *Her-2 negative*), she again goes back to the London clinic i.e. the stage of selective excision. In that case i.e. in last stage the only option the then doctor suggests is of "remote sympathy". He shares the inability of biological sciences to explore the reasons for diverse nature of cancers but ascertains the biological recognition of its dubious eradication. He challenges the idea of conquering the disease and seeks a revaluation where the triumph would be synonym to choice, the choice to prolong life or the choice to rule out death (ibid. 465).

Coming back to Jain (2013:33), who does not lay out such clear choices instead creates a cultural complex of cancer, the metaphors are important.

> “Cancer appears only at the nexus of our ways of thinking about it. I don’t mean to argue that “it” doesn’t exist, or that it doesn’t maim and kill people. But it can’t carry meaning outside of the meshy nets we use to locate and describe it. ”

Cancer is seen as a disease that acquires a life of its own by conquering over the human body (Sontag 1990, Mukherjee 2011), not that the human mind remains untouched by its engulfing nature. Our society talks about it in terms of its invading nature, the patient is constantly fighting with, losing their lives to cancer or emerging as survivors conquering it, the scientists are challenging it and further exploring it, doctor’s trying to defeat it, the private industry trying to bank on it and so forth. As I travel everyday around Delhi, huge advertisements by a known hospital suggest people ‘to rule out cancer before it rules you out’. The entire discourse provides agency to cancer by promoting pink ribbon campaigns, marathons to bring home the awareness drive, displaying blurred images of charred lungs on cigarette packets etc. The way cancer is reified in its everydayness and its banality is best witnessed from the regular lives of very regular people.

Living with cancer: Is it a different life?

In a cancerous tumour, cells undergo uncontrolled proliferation as per their own whims and fancies. Ironically, they are produced against and in the same body they have constituted. Other than the physical manifestation, Toombs (1992: 172) emphasises the self-identity as well as the social character of the body in the times of illness. The literature in anthropology and sociology (Leder 1992, Mol 2002, Lupton 2003) critiques the history of medicine for its indifference towards the social character of a disease/illness. The criticism is based on the socio-cultural iterations governing/guiding or manoeuvring the human experiences of physicality, spatiality, temporality as well as materiality while simultaneously collating the emotional. Cancer is not a singular unit; instead it has different meanings for different individuals putting up with different situations. Situations do not arise in a vacuum and are very much time and space bound and equally contingent upon physical and material sociality. The previous chapters delved into these situations and illustrated the sociality of cancer and its impact in the day to day lives.

The work was an attempt to explore the idea of temporality of cancer through categories of patients and survivors, the latter is understood as being disease free in the technical parlance whereas a patient undergoing treatment for years due to a gradually progressing cancer remains a patient throughout her years of living. In case of survivors, the moment of relapse brings them back to the category of a patient. The lives affected by cancer at different stages of prognosis beginning from diagnosis, during the treatment, immediately after the treatment, basically through the multifold layers of remission and relapse as well as amongst the survivors present the people with a confused as well as fluid understanding of wellbeing. The temporality of the disease creates a threshold and keeps producing and reproducing ambiguous categories. In addition an understanding of living with cancer through the notion of spatiality in the everyday context of the lives of people living with cancer came into light. Spatiality, as is understood here, has to be seen with reference to the notion of mobility or immobility of human body and the associated dependence. It can also be analyzed with respect to the isolation due to stigma and humiliation. The use of material aspects with respect to the changes in human body due to a serious illness present newer interface of meanings. The idea derives its basis from actor network theory which throws light on the role of animate and inanimate objects in a social world. Annemarie Mol’s (2002, 2008, 2010) body of work wherein she enunciates upon the multiple interactions of a body and the respective meanings is a case in point.

The analysis, though, must not be confused with Sontag’s (1990:14) work where she addresses cancer as a disease of space for the reason that it grows inside the body and is surgically excised and in certain cases results in amputation (ibid.). Here, the work discusses the features of temporality or spatiality in a different order which derives its basis from the lives lived by people ‘with cancer’ instead ‘of cancer’ per se. The narratives of pre-existing notions before a confirmed diagnosis and the transitory nature of practices and perceptions with the advancement of a terminal prognosis demonstrate a constant negotiation to survive. Fassin’s (2007) account was about people’s willingness to survive, the hope to sustain despite being aware of the impending death. Here, the people are hopeful not about surviving in the face of a terminal diagnosis but of being able to execute choices and control till they survive. The prescribed death knell and the precarious growth of cancer often befuddle people but it instills a sense of triumph too as we understand from Susan’s story.

During the fieldwork, my collaborators often shared their stories beginning from the period of diagnosis. While in certain cases the patients were still trying to cope up with the shock of diagnosis as I joined the team from the first visit, in others patients were either undergoing treatment, recovering, dying or completely recovered. It must be noted here, that remission, relapse, survivorship were very overlapping conditions with fuzzy boundaries and no discreet categories. During the interactions the understanding of cancer emerged in the form of multiple representations of cancer in the field. These four categories are based on people’s reactions to the disease. The categories are; a) Surviving cancer: a humble reminder and a stark reality, b) Living yet not living, c) Normal or diseased d) The endings. Parts of these interactions have been discussed in the earlier chapters. The purpose of this chapter is to cover the miscellaneous yet significant acts of cancer representation through small ethnographic accounts.

The grand narrative of cancer and the liminal short stories

As a student of anthropology, in my under-graduate days I tried to understand the literary relevance of the theory of liminality through a comic explanation where I understood liminality as a micro level theory that breaks into a grand narrative without harming the short stories, it instead provides significance to the short stories as well as provides them with a base, a common ground to hold on to. This forms the ground of transition. Here, I would like to experiment with a similar deconstruction of a grand narrative of cancer and derive the shorter stories that make it a whole. For the survivors, cancer renders a sense of familiarity with the fear of death. The familiarity doesn’t pose an existential threat instead cements the notion of inevitability of death. The narratives from the field, on one hand, reflect upon the death causing notion of cancer yet simultaneously rule it out as the only cause of death. I do not intend to talk about dying and the further difference between death and dying in this chapter. The narratives have a tacit sense of assured character of death as well as a precarious nature of life. When the larger understanding of cancer demonstrates the negatives, the understanding of the disease in its local representations sense can be see as a positive by which I do not intend to imply any sort of glorification but the ability of human populations to sustain in the face of struggles.

Surviving cancer: a humble reminder and a stark reality

People diagnosed with cancer face this constant sense of uncertainty due to the phases of remission or relapse. People who are living a cancer free life present a different perspective to this sense of uncertainty. Harmala Gupta in her interview shares,

> ‘I was granted vision for a moment (while speaking about her own illness), which allowed me to understand life and its uncertain nature. Pursuing regular follow ups is a healthy idea and each of us should be provided with provisions to undergo regular check-ups, it is nowhere scary. The ‘what if’ (my cancer strikes again) situation holds good for each of us, with cancer, without it too.’

Many cancer survivors shared similar approach towards life. An improved lifestyles in terms of healthier diets, regular exercising, yoga and conscious efforts to avoid stress by avoiding ‘negative people’, pursuing regular follow ups, engaging in the idea of spirituality, and the notion of self-love are mentioned as a few transitions they had observed after recuperating from their treatment. Some of them, while sharing their moments of treatment, were reduced to tears. As Seemakshi, a mother of a thirteen year old boy (now) and a survivor of osteosarcoma, who lost her leg to an amputation ten years ago, speaks about her cancer,

> ‘I am not crying because of any remorse, now what to be sad about? Tears come up thinking about something which was to be lost. (Pauses to wipe her face). Its ok in others case but if you see it (cancer) through your own eyes, the meanings change. I had heard that you die(of cancer) However, the thought that I was going to leave behind my baby so young was troubling. I used to cry a lot

> thinking of him. Now he has grown up, everything is alright.' ("*Rona dukh se nahi aa raha, ab kaheka dukh. Aansu toh bas yeh sochke nikal aaye ki jeevan khone se bach gaya*. (pauses and wipes her face) *Auro ke like toh theek hai par apni aankh se dekhlo toh, itna paas se toh maane badal jaate hai. Mar jate hain humne yehi suna tha. Bas bete ko peechey chhodne ka dukh tha, itna chota tha. Iska soch ke khoob roti thi main.' Ab to bada ho gaya, sab theek hai.*")

Anandi in her early forties now, was diagnosed with colon cancer almost ten years ago. She underwent a surgery and recuperated and has been struggling with other issues in her life, including no source of income, domestic violence, an extra marital affair of her husband and her broken relationship with her own brother. After ten long years, in the year 2014, she felt excruciating pain and underwent a few tests to find out a relapse. She underwent the surgery around the time I left my field and her experiences could not be chronicled any further. Nevertheless, in our initial meetings she openly shares her fear of a relapse and subsequent death. On asking if she is scared of dying given that her children were still very young, she shares,

> 'I am not even sure if I shall be dying. Cancer does not guarantee death, it is a may be and may not be type of situation.' ("*Mujhe toh yeh bhi nahi pata ki marungi ya nahi. Cancer se koi pakka nahi hai mar jaate hai, ho bhi sakta hai nahi bhi.*")

Similarly, Kundan with cancer of the inner lining of his kidney is undergoing treatment during my fieldwork. When I am to leave the field, he and his wife express their desire to meet me ‘one last time’. I meet them and make sure to ask what they mean by ‘one last time’. To which he replies,

> ‘ it is not the cancer but life that is uncertain. If not cancer it can be anything.’ (*“arrey cancer nahi, jeevan ke liye keh rahe hain. Cancer nahi toh kuch aur ho sakta hai”*)

His wife, however, shares on an emotional note that all his reports have been good and still he is mentioning ‘death’. To this he reacts to his wife by saying that ‘he has learnt it the hard way *(“mushkil se seekha hai madam”)*.

Normal or Diseased

The narratives in this category largely come from the survivors or from people having a stable prognosis with a gradually growing cancer. Also, such stories are generally shared by people who bear visible marks on their body, demonstrating treatment/intervention. Knowing fully well that the tumour has been excised from the body, many of the patients accept ‘half -baked/ incomplete yet fine’ (*“kacha pakka/ adhe-adhure par theek hai”)* nature of the sense of normalcy. Tanisha and Khuhsbu are two young girls aged seven and twelve. One recuperated from leukaemia while the other is recovering from brain tumour. Tanisha, goes to her school, plays with her siblings and has recently received a bicycle as a gift from the organisation. Every time we go to her place, we make sure to carry chocolates for her and her siblings two of whom are younger to her. She understands that she was very sick and has been treated successfully for now when she excitedly says, ‘earlier I was very sick but now I am completely fine.’ (*“pehle bohot bimar thi par ab ek dum theek hu*”)However, she knows her sickness has made her parents extra cautious towards her health. Despite being ‘very poor’ (when she understands, ‘mommy papa have very less money’; her father is a daily wage construction worker) she knows some of her demands will be fulfilled and if that does not happen she feels that she will be sick again. The child knows to play the game by her rules, as everyone understand it, but no one says it openly. Despite staying in utter poverty, parents make sure Tamanna is never deprived of her playful demands. The sense of normalcy in her case for her parents is often not purely normal. Her siblings are aware that she is never denied anything. As they share, ‘no one says no to her’ (*“isse koi mana nahi karta”.*) Khushboo (whose father works as a guard at night and, therefore, sleeps in the daytime) on the other hand, never demands anything. She is aware her father’s salary will be wasted. I ask her what she really desires for. She answers shyly, ‘hair’*(‘‘baal”)*, ‘earlier I had beautiful hair but now I have lost them. I do not like going out except for my school (“*‘pehle bohot ache the, ab chale gaye. Main kahin nahi jaati, siwaye school ke”)*. With a cloth tied over her head in the month of July (which is hot and very humid), she was sleeping inside a small room with five more family members as we knock the door. The counsellor suggests her to take of the cloth when at home but she refuses smilingly without making an eye contact and then whispers that her brothers call her ‘bald’(“*ganji”*). She has returned from school after giving an exam (mathematics). I ask if she likes going to the school. To which she replies, ‘school is good. I have a few friends who have hair’ (“*acha hai, mere thodese dost bhi hai, baal hai unko”*). The team assures that her hair will come soon and this time more beautiful as is with most of the people who undergo chemotherapy. Her mother says but she had brain surgery for which they have cut her skull. The team says, that will not hamper her hair growth and assures them that they have seen many patients who underwent brain tumour surgery and now have ‘beautiful dark hair’. For Khushi, her normalcy is contingent upon getting back a head full of hair.

Similarly, Prakash who stays in Old Delhi and is a patient of multiple myeloma works in a private firm as an accountant. In his early fifties, his sons are pursuing education through correspondence and work in call centres. He goes to his office as much as possible and goes for his chemotherapy all by himself too. A patient of multiple myeloma, he gets tired but nothing much. He has been seeking treatment for a year now and cancer has become an ‘general ailment’ (“*aam bimari”*) for him as he shares,

> ‘after my diagnosis I thought I have very less time at hand but it has been over a year and I have been functioning normally with occasional discomfort. I do not know if I am really a patient of cancer; I pay bills, go to my office, bring grocery like anyone’. (“*pata chalne ke baad mujhe laga kam samay hai par ab toh ek saal ho gaya aur main aaram se kaam karta hu. Kabhi kabhi takleef ho jati hai. Mujhe pata nahi main cancer patient hu; bill bharta hu, office jata hu, ghar ka samaan bhi, aur logo ki tarah.*”).

Similarly, Seemakshi asks me to touch the lower side of her abdomen. There is a solid mass inside and I give her a puzzled look. It is a morphine pump helping her with pain control. Pointing towards the amputated leg and the pump she states that,

> ‘these things never let you forget. I am a jovial natured person but time changes, even this is good.’ (“*yeh bhulne thodi deta hai. Woh toh main khush rehti hu par time badal jata hai, yeh bhi theek hai*”)

Patients often share that surgeries performed to excise cancer are strong reminders that ‘cancer occurred once and can occur again’ (“*ek baar hua hai dobaar ho sakta hai*”). One of the patients I met only once and asked her how is she post-surgery as,

> ‘yes. Everything is normal. Only that I do not have a breast.’ (“*‘haan theek hai sab, bas chhati (breast) nahi hai ek*”)

Having undergone a mastectomy she stated that this did not affect her. As per her, she is a middle aged (“*aadhi umar nikal gayi”*) woman and not a young girl anymore and is a mother of grown up children ‘who don't need to suckle’. She shares of never being conscious of public appearances yet while taking bath it reminds her of the transition (“*kuch badal gaya hai*”). Also, as she has met with many other women whose cancer relapsed (“*dobara ho gaya*”) she shared that she understood that her disease is in a state of flux (“*aane jaane waali bimari*”).

Parvez (42 years) shares that he is a normal person, has undergone close to sixteen surgeries since 1998 and his entire body bears stitch marks all over. He drives a vehicle for transportation of certain goods and has a relapsed cancer in his left hip. His pain, as per AIIMS, is on the higher side of the pain ladder and he must take regular doses of morphine. He skips the doses to avoid sleepiness while driving and is used to his pain. He calls himself as normal as anyone else with his work schedule and everyday life but his body (“*kati- phati*” cut and mutilated) is a reminder of living with cancer over the years. For the very reason, he has decided not to undergo the entire leg amputation suggested by the doctors very recently (2014) as he does not want any more cuts and dissection on his body.

The patients who undergo ileostomy/ colostomy (removal of small or large intestine) are often found to be a little reserved, especially women. In their case, they need to constantly wear a colostomy bag that stores the stool outside the body. One of the lady, who has survived for more than nine years, barely discusses about her ‘disease’ (“*bimari*”) when we visit her. The nurse warns me not to mention ‘cancer’ at all. She allows the team inside only if she needs ‘medicines’ or wants to get her blood pressure measured. Once she shares with the nurse that,

> ‘even if you survive certain things change forever, only one who undergoes the treatment knows what they loose, it is never the same again but you stay alive. Initially, I had issues (keeps a hand on her stomach where she has the stoma) but no more. But I do not like anyone mentioning the name of the disease.’ (“*aap bach bhi jao toh badal toh jaate hi ho, jiska ilaaj hota hai usse pata hai kya jata hai. Pehle jaisa ni rehta but zinda rehte ho. Shuru main dikkat thi mujhe (keeps her hand on her stomach where she has the bag), ab na hai. Par acha na lagta log naam le bimari ka*”)

I dare to ask ‘why?’ to which she replies, ‘it is a filthy disease’ (“*gandi bimari hai ye*”) The counsellor shares that once she had shared that she avoids the mention of cancer to everyone for reasons related to ‘identity’ (“*pehchaan*”): ‘you become a patient for everyone’ (“*Aap sabke liye mareez {patient} ban jaate ho*”).

Cancer changes the way of living by incorporating the material modes of sustenance to the very intimate bodily realities. Catheters, tubes, diapers, patches, stool bags, prosthetic bras acquire an essentialist life through the people who live with them and one doesn’t need to get back to a philosophical enquiry of artefacts but to understand the relationships emerging through the interactions between human and non-human. These interactions are as much a ground of hope as of stigma. For instance, the prosthetic bras and breast reconstruction surgeries fall under the feminist scrutiny all the time. It forms a popular debate and the team members in the organisation often blindly give suggestions to patients for hiding the flaw 'it won't be noticeable you can wear it ("*pata nahi chalega pehen lo*"). The prosthetic helped many women overcome their insecurities and ill-fitted dresses (as many women patients and team members would often share). However, in many households, where women were either less educated, belonged to rural areas, had already fulfilled their breast feeding responsibilities often denied such a proposition. As a woman questions, 'who used to wear it earlier' ("*pehle kaun pehnta that?*"). There were reactions like, 'Now it's not needed' ("*ab zarurat nahi hai*"), 'have never worn it' ("*kabhi pehni hi nahi*"). Such reactions were accepted without any exclamations, but a counsellor pointed out to the need of initiating the proposal on the part of the teams. He critiqued it by calling it a 'western understanding of appropriateness of garments and bodies' ("*kapdo or body ki western understanding pe hum log bhi ladies ko option dete rehte hain bina soche ki kya unhe yeh chahiye?*"). As much as some people had concerns over the social stigma due to the external addendum's, there presence was appreciated in retrospection.

Living yet not living

Murphy et al. (1988:235) points out the shortcomings in the social déviance model used in sociological researches to characterise the status of the physically impaired. They offer a model from the anthropological study of rituals.

> ‘The disabled are viewed as being in a ‘liminal’ state, as in the liminal phases of rites of passages. They are persons having an undefined status: they are neither ill nor well, neither socially alive and active nor socially expunged and removed.’ (Murphy et al. 1988 : 235)

During the fieldwork, many people with cancer were bed-ridden and entirely dependent on their families. Some of them were quadriplegic and paraplegic while some had their legs replaced with metallic rods and awaited the moment they could stand by themselves. The wait was desperately long and frustrating for some while others wanted to hold on for as long as possible. Kirin, a woman in her thirties and a mother of four children, who worked as a domestic maid before she was diagnosed advanced cancer in her lower right leg, was bed ridden, unable to move her lower extremities and suffers from immense pain. With her very young children assisting her with toileting needs she shares,

> ‘either God should cure me completely or call me. Such a life is no life, death would be better than living this way’. (“*ya toh bhagwan theek karde ya bula le. Is bimari se toh zindagi nahi hai, marna behtar hai aise jeene se.*”)

Suresh with the metastatic cancer of vertebral column, has similar concerns too, a paraplegic, he is on bed for almost a year now. He met with an accident before his diagnosis and suffered from multiple fractures in his vertebral column making him bed bound. With only his hand and neck movement, he calls himself a

> ‘a living corpse with a functional tongue, adding that death is desirable than such a life. These madams (pointing towards the nurse and the counsellor) will not even poison me, no one worries about me.’ (“*zinda lash hu, bas zubaan kaam*

> *karti hai. Marna acha hai aise jeene se, gandi bimari hai, yeh madam log (the nurse and the counsellor) bhi zeher nahi deti, koi nahi sochta mere bare main*")

Similarly, Hem (in his sixties) who is suffering from AIDS as well as throat cancer, shares his concern stating that he has been doubly punished for his wrong doings.

> 'have been punished twice, AIDS and cancer both)'.(" *do baar saza mili hai, AIDS aur cancer, dono*")

He states that 'though alive, he died every day; of guilt'. Considered his life as a death sentence he had attempted suicide twice.

Amar's wife, Chanda, is his primary caregiver, while he suffers from oral cancer with an open wound on the left side of his cheek and three perforations on his neck making it difficult to speak. Unable to open his mouth due to the growing cancer and the fetid smell, his wife speaks on his behalf. While she wants him to live, she has found out from her neighbourhood that

> 'cancer patients often suffer from non-healing fungating wounds which putrefy and are often inflicted with maggots.' ("*cancer walo ka zakham nahi bharta, sadta-galta hai, badboo aaati hai or keede bhi pad jaate hain*").

She states that in such a situation, his life would be worse than a stray animal, "*awara jaanwar*". It is better if he dies before such a condition arises.

These narratives, sometimes directly and sometimes indirectly, hint towards the liminal nature of the life course and the changed meanings of 'normal' despite having a prolonged survivorship. A better understanding of the liminal nature of the lives of people who have cancer can, therefore, be a suggestive component for a more nuanced care. The statement below mentions it for ‘nurses’ but it is equally desirable on the part of doctors and counsellors and other health practitioners to acknowledge liminal nature of lives in the case of life-threatening disorders.

> ‘Liminality calls on nurses to more consciously listen to patients’ narratives in ways that hold contradiction without needing to resolve ambiguity or paradox. Nurses can be more sensitised to that which does not fit into categories by understanding liminality and thereby recognising possibilities of certainty and uncertainty at the same time.’ (Bruce et al. 2014: 42)

Cancer if understood through the above narrative categories presents itself as different entities influencing people’s life through multiple representations. This understanding can lead us to a metaphoric reality of cancer which is often criticized yet used in one way or the other. The above narratives represent the notions of cancer among people in different stages. The concept of pervasive liminality can be used to understand the basis of such segregation. Pervasive liminality differs from liminality a term coined by anthropologist Van Gennep (Turner, 1967) who used it to identify a transition in rituals “betwixt and between”[47] pre- and post-ritual states. His conceptual model of rites of passage included three phases: separation, transition (liminality), and incorporation. Turner (1967: 96-97) furthers the idea within the anthropological context and refers to liminality as a space where people are ‘neither one thing nor another; or maybe both’. Bruce et al (2014:37-

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[47] For a detailed review of the concept of liminality in life-threatening cases, read Bruce et al (2014).

38), mentions the condition of pervasive liminality and distinguishes the concept from liminality by stating that,

> "the notion of pervasive liminality is intended to differentiate these experiences from a more frequently used notion of liminality as an in-between phase in a multistage process such as life pre-diagnosis, diagnosis, and post-diagnosis. Pervasive liminality points to stories that convey being in the midst of what may otherwise be seen as discrete experiences that overlap and fluctuate over time."

Observing death

The field was a mixed bag in terms of reactions, experiences, beliefs and awareness leading to chaos in the individual units of the households or patients and the key task of palliative care teams was to acknowledge the struggle of people through the chaos. The people knew the probabilities of two things for certain, the diagnosis and the death. What lay in between was not only the prognosis but a reminder of approaching death as the teams and the hospital prescriptions repeatedly situated through their actions, verbal and non-verbal. It was on the contrary a continuum of fraying and revival of persistent human logic of knowledge and practice. Here, I do not stress the significance of the role of patients unlike in the field where they were prioritised for obvious reasons in provider-clientele relationship. I see patients as the catalyst for enabling a confrontation of hierarchies. The hierarchies were not out rightly resistant in nature yet the subtle inter-play of resistance marks one of the central representation of the world of care and dying. Death ousted this interplay for the reasons that the patient vanished and the interactions suddenly acquired a relatively more dominance on the part of the families. Quite a few families communicated their disinterest in the bereavement visits over the phone; the teams would convince them for the sake of fulfilling their own professional interests and would express their surprise with a sense of self-pity. The relationships between the teams and the households largely drew its cement on the basis of time spent together. During my time in the field, I repeatedly visited the same households while accompanying the teams to the newer ones too. The teams arranged the visits in such a fashion that I could cover the same households every week. There were advanced terminal diagnosis, quick deaths within weeks in our visits. The teams were always active and made sure to stick to a few basic protocols other than providing symptomatic relief, breaking the bad news[48] was the most important step. This was for two reasons; firstly many of the nuclear families especially in the urban corners of Delhi shared their lack of awareness of how death happened, the villages as well as families with stronger associations with extended families were more perceptive of the approaching death and secondly, the dying and their families often shared their desire to 'be at home if anything happens'. I would ask the families how they came to know that the death was approaching and what made them decide not to rush the patient to the emergency and many replied that before rushing to the hospital they thought of calling either the nurse or the doctor, which was possible because of the provision for 24 x 7 on call availability. During the bereavement visits, I found my initial discomfort with addressing questions regarding the recent death to be rather obvious for the reasons that I found it a little insensitive to still be the exploring ethnographer but later I saw it as a part of my

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[48] For more on this read Gawande (2014). Aulino (2012) cites MJ Good (1994) work on the comparative perspectives in the east and west about sharing the information with the patient related to her diagnosis and prognosis. She mentions the prevalent palliative care and end -of-life-care

familiarising process with the field. The families and the dying expressed their stronger reliance on the teams rather than the hospitals. The teams had suggested the families to take the patient to hospitals too when they felt indecisive. But the communication never bore a hierarchical order, it was instead more about trying to grasp the prevailing tension in a situation and reflect accordingly and the last choice was left with the patient and the families.

Many families shared their sense of contentment of losing their loved one in front of 'their eyes'. The grief of caregivers was much aggravated and had a sense of guilt where death happened outside the home. In some cases, the patients insisted on calling the team in their last hours even in the wee hours followed by requests for a last visit before the final moment. Families based on their ability to perceive and their awareness of how death happened would sense that the time was close. For instance, the disrupted breathing and the gurgurating sound was stressfull as well as an indicator. The families tried to seek medical help in some cases but in cases where people are able to perceive that the death was near the families decided to sit by the side of patient and provide comfort by holding hands, opening windows for fresh air to come in, arrange pillows so that the head is a little elevated, playing mantras on a laptop, pouring holy water and praying, preparing something for them to eat if they demand (all these acts were shared by the families while describing the last moments of the deceased member). The teams played a key role in cases where they could elaborate the families on how death occurs; this often required a longer association. In case of this study, families shared their 'sense of "*tasalli"* (contentment)' to see the patient fully aware of his surroundings. The families who were unable to witness this sort of an experience expressed a sense of 'only if it may have happened'. Strangely, the last hours of patient discomfort which were mentioned as a 'little bit of problem' were often contented with 'death at home'[49].

The chaos at the moment of death can be interpreted in multiple ways. The patient discomfort in certain cases led to hospital visits whereas in other cases it led to an opposite understanding of creating an ambience for peaceful death. The chaos may have been more in case of death at home with families undergoing emotional crisis by watching their loved one die but in the later visits there was a sense of finality. When compared to the cases where patients died in hospitals or on their way to hospitals, the regret of a death outside the home was often mentioned. If understood this way, chaos brought a sense of stability. The field experiences in case of this study were about facing the chaos and making sense out of it. The families who shared their lack of awareness over the signs of an approaching death have lost their association with death in a similar fashion the westerners are made to forget.

The experience of witnessing death by being around the patient was seen as an assurance of loss as people often used the phrase *'aankho ke saamne gaye'* (died in front of our eyes). For instance, a patient whose children had been staying abroad over the years, passed away at her home where she lived with her husband. On one of the bereavement visits, her children shared their sense of disbelief as they could not attend the cremation because of work commitments and the ritual was carried out by the husband in their absence. Not being able to see the dead body and the process of death can have long term bearings on coping up with the loss.

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[49] Elana Buch (2013) refers the phenomenon of sustained personhood explaining the deep desires of the patient to stay at home till her last breath in the context of American women living with breast cancer.

Indian traditional households are patriarchal in nature and the position of the patriarch often has its bearings in the case of his death. For Rama and Chandrakanta, the two caregivers who lost their husbands to the disease, in front of their eyes, at home, the sense of insecurity was difficult to cope up with. In case of these two women, in their early fifties, 'life lost its meaning'. The loss was not corroborated on emotional grounds as much as on the criterion of a widow, a woman without a man. The women shared that it is difficult for a woman whose husband dies before her to gain respect within the family as well as outside the family. They feared facing neglect at the hands of their children. Chandrakanta had support of three children while Rama lost autonomy in the house, financial as well as domestic. Death made them perceive themselves as vulnerable to the society and their family[50].

This discussion appeares in the end for the very reasons that living with the disease and negotiating the everyday realities are often understood meaningfully through the process of care till the end. Care renders an agency to the debilitating bodies and dwindling hopes to navigate through, as we saw in the last chapter. In the case of advancing cancer, however, the hope is never for survival but either for sustenance without suffering or an end. The anticipation of finality, for how long one stays hanging in there? The finality which is feared upon yet accepted for its universality and certainty. The certainty bears

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[50] Willmott (2000) calls for a shift in sociological theory for understanding death as it perceives death in negativity, and forgets its emancipatory existence. As per him, 'sociological studies come up with modern strategies for coping up with death but they also contribute to its sequestration as they routinely naturalise the contemporary common sense understanding of death as something negative that must be coped with and calls the morbid representation of death is a social product. I would say that this representation is often an outcome of the feared consequences instead of the fear for death. Seale (1998:1518) explains that death threatens the orderly continuation of social life, especially in societies heavily dependent on the personal qualities of individuals. The death of a loved person can disrupt a basic sense of security about being in the world.

the most uncertain character though. The suffering patient hears the death knell every day while flickering through and awaits the moment of release.

Also, the terms used to address death can throw light on the meanings associated with it. In the field, people referred to it as *mukti*[51], *khatam ho gaye* (as in finished[52]), *chale gaye* (left) or simply as 'death *kar gaye* or death *ho gayi*' (he/she died). It is interesting to share that most of the families of the deceased-patient-collaborators never mentioned their death with its equivalent in Hindi lexicon *(maut, mrityu, mar gaye)* immediately after the death or in the course of mourning over the loss. The terms of referral brought in a sense of emancipation unlike the usual meaning of associated to death in the western literature, something that is feared upon and is associated with loss. The finality of a suffering body if understood as a moment of release in the this context makes us comprehend the essence of death as an end to patient's struggles with a diseased self. The term *'mukti'* was often used by the families and friends of the deceased whereas the formal caregivers also used it in occasional cases. Otherwise, for the formal care givers the term of explanation was 'death'. During casual conversations, however, the team members would often be heard saying, 'should attain mukti' ("*mukti mil jani chahiye*"), 'should leave now' ("*ab chale jana chahiye*"). As a protocol, bereavement visits were conducted after the family was able to observe the mourning period so as to allow families to come to terms with the loss.

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[51] Unlike the mythological understanding of the term *mukti* where it implies release from the birth cycle and is confined to a hindu understanding of death. In the field, the term was used by people from different religions and was understood as emancipation from the suffering due to cancer.

[52] I see this term as bringing in a sense of completion or conclusion.

Pursuing closure, exploring grief and understanding practice: Mulling over the methodology

Once the fieldwork was over and I returned to write about it, the teams and families would call me to inform about the patients I was in touch with for the longest span. These patients were aware of their dying process and acknowledged the inevitability of death yet survived through the time. Over a year, the team informed me of fifteen patients who died and shared that some of the families expressed their desire to meet me again. After a year of writing a draft, I visited the field again for three weeks and met the families without the patients. The members were more stable while sharing their grief unlike my earlier interactions where the idea of approaching death stirred emotions.

A fieldwork observing prolonged intimate encounter with the dying and their families problematises the exit from the field. A physical withdrawal was possible by citing the completion of the process of data collection but an emotional disengagement[53] required saying 'proper goodbyes' and distantiating oneself gradually. The last four months observed a detailed focus on the activities and experiences of the team members working across Delhi. The interactions with the formal care givers were conducted later so as to gradually disengage from the patients and their families at an emotional level. But it so happened that some of the families lost their loved ones in the same period and it was time to begin with thesis writing. The families tried to get in touch and were assured of later visits. After a year, the opportunity to revisit the field arose but by then the teams had stopped visiting the families as the 'patient' was no more. The challenge, therefore,

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[53] For more read Sonia Allen, Ysanne Chapman, Karen Francis & Margaret O'Connor (2008) Examining the methods used for a critical ethnographic enquiry, Contemporary Nurse, 29:2, 227-237

was to meet the families of the deceased all over again and explore the experiences of living with loss after the bereavement visits had long been finished and the files closed. The team members often explained that their job ended as soon as the patient passed away and usually after one or two bereavement visits they stopped visiting the family. Some of the team members expressed their remorse to the fact that after developing an intimate bond, the death of the patient often disrupted the ties suddenly. In such a case, the revisit also brought in a sense of closure when some of the care givers mentioned phrases like , ‘now you won’t come anymore’, ‘so this ends finally’ , ‘this is your home too so keep coming but it gets difficult to meet once the work is over, ‘try to call and be in touch, he left but we are still here’ and other similar expressions.

Most of the respondents had passed away in my absence so while revisiting the families I decided to engage in conversations and listening to them intently, making notes, maintaining a field diary as well as a second set of writing about the personal positionality (a term introduced in ethnographic discover by Rosaldo, 1989) in the field. Audio-recordings were not carried out during these bereavement visits for moral reasons. Many families expressed their relief over the prolonged and tiring care work, many were able to give a fresh start to their lives but some were deeply grief -stricken and were labelled as sufferers of ‘prolonged grief’ by the counsellors in the teams. In the interactions with the staff members and volunteers of the organisation, some of whom had either lost a child, a spouse or a parent, they shared that overcoming the grief was a painful process and in many cases the struggle was never to overcome the grief but to channelise it positively and get accustomed to the absence of the deceased.

When anthropologists talk of thick description, expressing grief and understanding its intensity are equally challenging. As Rosaldo (1989) questions, ‘do people always in fact describe most thickly what matters most to them?’ So, when it is not thickly described how does a researcher prod the matters and further address them in writing? Is reflexivity a narcissistic pursuance or a relevant addition to the ethnographic writing? Also, do personal experiences of an ethnographer act as reference points for explorations or as a point of hindrance? Barett (2011:478) cites Murphy’s experience of the progressing disabilities from his auto-ethnographic account and concludes that the dying people “live through the existential experience of disembodiment”. The author (ibid: 478- 479) reviews the anthropologists personal account of experiencing dying and bereavement through the work of Rosaldo (2004), Panougia (1996), Wikan (1990) and Shostak (2000) who reflect upon their own loss in the field or their struggles with a terminal illness while trying to engage themselves in the field. She does so to emphasise our own mortality and with the purpose of pondering over the “challenges and possibilities of conducting an experience near ethnography of dying and loss”. For instance, when Rosaldo (ibid) speaks of grief amongst the Ilongots, he shares the idea that one can actually understand and reason the rage behind the act of head hunting only by experiencing loss in their intimate lives. Anthropologists like Rosaldo (ibid), Behar (1996), Shalinsky (1991) have collated their personal experiences with the theoretical understanding within the discipline to reflexively engage with ethnographic writing (Kleinsasser 2000). Gillian Rose (1997) argues that ‘calls for reflexivity have too often implicitly invoked claims to what she calls “transparent knowledge”, namely the idea that researchers can be all-seeing in their reflections on the dynamics of research relationships.’ She rejects it stressing on the fact that no-one has access to such a perspective, and she argues instead for an approach that acknowledges the inherent limits of reflexive insight and calls reflexivity a ‘double-edged sword’. In a similar vein, Wanda Pillow (2003:188-192) calls for a move away from what she calls “comfortable” uses of reflexivity towards “uncomfortable” reflexive practices that disclose the “messiness” of research and actively unsettle or disrupt the processes through which knowledge is produced and warranted. These critiques suggest that practising reflexivity effectively is difficult and complex. Pillow (2003) perceives the risk that reflexivity is reduced to confession, catharsis and/or cure for the researcher, and fails to add anything of substance to the research itself.

> “The problem is not that we tailor but that so few qualitative researchers reveal that we do this work, much less how we do this work.” (Fine 1994)

During the last leg of my work, addressing and exploring grief appeared to be impossible. As an anthropologist, I am not equipped with the psychiatric tools used to measure such emotions and I am equally vary of such measurements for the reason of quantifying human emotion using graphs and numbers is uncomfortably astute scientism. And as an individual, I have always fallen short of words and ways to communicate with the bereaved. Grief may or may not be shared with others and this complexity leads to difficulty in exploration and interpretation. The researcher’s task to explore it, therefore, requires venturing into uncomfortable emotional zones as well as relying on long pauses, personal and the others in the conversation. I therefore try to look into the stories from the field and simultaneously elaborate upon the researcher’s interventions and inhibitions during the process of exploration.

Interacting loss

A fluid interaction;

We visit her home after almost six months since her demise. Her husband, who is in his early sixties, has been waiting for our visit since morning and is eager to sit and talk. After exchanging pleasantries, I enquire him about his general health, how has life been since he lost his wife, how was his last interaction with her? He shares her last moments. The night she passed away she asked him to sleep next to her and hold her body. Since both the sons were sleeping in the same room, he asked her to sleep quietly shying away to lie by her side in what he perceived as an intimate posture. She kept insisting and said that he doesn't love her anymore and dislikes sharing the bed as it gets dirtier with the fluids oozing out from her wound and her problem of incontinence. He gave in to her request and lied down next to her on the same bed. After almost two hours, she asked for her sons to lie next to her too. Her husband woke them up and all of them slept by her side, holding her body to assure her of their presence. After sometime, she began to gasp for breath and they decided to call for an ambulance or a taxi to shift her to a hospital but by the time the vehicle arrived, she had passed away. As he finished his narration, I decided to take out my pen and note pad and jot down some parts of our conversation while they were still fresh in the memory. His wife suffered from a mental disorder which had led to loss of coherent thinking and broken speech, she suffered from a paralytic attack which crippled her right side of the body. As the family cared for her even before she was diagnosed with cancer, I ask the husband if he ever regretted not being able to do much due to financial constraints and how he would like to reflect upon her wife's sudden vocal demands moments before her death.

> ‘None. (Referring to the regrets, he exclaims smilingly) I never expected that she will express herself to such an extent before leaving us. It was after a very longtime that she could speak so much. Off lately, she used to ask for food and would prompt us whenever she wanted to pass stool. We did all we could. I never realised she had an understanding of her disease, or the fact that her sons and I would take turns in bathing her, cleaning and dressing the wound on her breast, help her in attending the nature’s call but in retrospection, I think she understood all of it.’

The teams usually never stay for this long for bereavement but to accommodate me they kept sitting there looking visibly bored, droopy eyed, famished and yawning while he shared his life post-marriage. My task was to manoeuvre the conversation with interjections. The interjections prevented digressions but also reflected an interest as well as an urgency to wind up the conversation. It was a selfish but desired move. He stayed alone as his sons have resumed their work completely. He further added,

> ‘I am sad to have lost her, she was unaware of her conditions but I was aware of our relation….(takes a pause, smilingly crosses his arms against his chest) Always. This remorse will last till I am alive, there is no work to do at home now that she is gone. I am absolutely free, I cook for my sons. Grief shall always be there, she was a member of this house. Due to a traumatic pregnancy, she had lost control over her senses, she could cook but I used to be vary of her getting near the stove/fire. I raised the kids and tended to her as well. Then she was paralysed on one side. A few years into the marriage and I developed a long

> association with illness and hospitals. Two years ago, I lost my daughter who was married for a year. This is my destiny, I do not cry but I remember them often, especially at night when I try to sleep. My life has been filled with grief but what can I do? Crying barely helps, you need to come to terms and make compromises. Or else life will be like stagnant water which can only stink. I was used to caring for her, suddenly it seems as if I have nothing to do.'

In the above conversation, the grief was openly acknowledged. He was extremely calm while sharing these memories and expressed his happiness over sharing his feelings.

Restrained grief or recovered self;

He passed away at the age of ninety two. He was diagnosed with oesophageal cancer almost a year back and he lived with his wife who is three years younger to him. Close to a year after his demise, as I revisit his house, his wife is living by herself and has a maid for domestic chores. As she notices me observing an old sewing machine with paddles, she speaks excitedly with a broad grin, 'Your uncle gifted this to me on one of our wedding anniversary.'

Further into the conversation, I feel ill equipped to satisfactorily engage with her. She speaks out of experience and in an assertive fashion often telling me I am too young to understand this. She keeps asking me to eat more snacks from the tray in front of me and gives me a glass of juice, and maintains an eye contact with the nurse and the counsellor. I try to observe as much as I can. It is similar to a scenario in many of the Indian households during my childhood where elders kept talking while the younger ones were supposed to stay quiet. Out of respect and sheer hesitation you are unable to break the decorum and if you try to probe, as I do once, you are subtly brushed aside. It must be added here, that the counsellor with us is new to the area and has not visited this house. So the interaction is largely between the nurse and the lady. I exchange a glance with the nurse during the conversation to hint her to probe about the experiences post uncle's death. The entire episode confirms to the fact that she came to terms with her loss and is stable with her emotions. The nurse asks what she thinks about staying alone. She replies,

> 'We lived together for sixty years and led a very happy life together. Had it not been him it could have been me. Any which way, you see, one was meant to be left behind. I do not want to leave this house and stay with my children, the home is his memory and I am sure he would not have left the house either had I died before him. This house if full of things he loved to buy, for the kitchen, for the living room, for the terrace. What to do, (shrugs off her shoulders happily and spreads out both her hands) life has to move on and it will.'

But does staying alone in this house makes her sad? To which she adds,

> 'The grief stays but good memories help. The grief is good too and is necessary too. It shows your bond with the person who passed away. It speaks of our relationship. And ninety plus is a good age to die. When else would you, otherwise? You will know it when you reach our age. Young deaths are painful. Loosing your spouse is awful, but what to do? We need to understand 'age' (*umar*), his condition had worsened and I saw him suffering in pain, it was good for him. I am glad he did not continue for long in his suffering (pauses for a second) that would have been unbearable.'

After a pause, she adds smilingly ‘we have a way with our heart (“*hum apna mann mana lete hai*), right?’ On our way back, the nurse shares her assumption that probably the lady was not willing to share much as she said,

> ‘Often, people do not like us to visit their houses after the patient’s death. On occasions, we have been told that a bereavement visit is hurtful and reminds them of their loss. Many of the families refuse for such a visit but as a part of the program we insist on at least one such visit as we need to close the file. So, after a nine month gap it is difficult for many to welcome us to their homes.’

I, on the other hand, found it to be a significant interaction as she was able to reflect upon a lot of matters, despite being succinct and disinterested as per the nurse. And her unwillingness to part away with her emotional privacy is a valid choice. Her narratives, however, reflect a strong will to understand and move ahead with the loss.

Emotional Bias

Each patient’s story is different. But he reflects those stories where the patients’ were either children, teenagers or of my age either unmarried or married. His young age did resonate with me at a different level than a few other patients. This can be seen as a bias but I tried to acknowledge it and overcome it. In a very few cases, I did break down and over reacted; for instance sometimes I was unable to write, was irascible and much worse. It took me time to realise this sudden change in the behaviour and I decided to write about my emotional connect whenever I felt disturbed in the field.

He was nineteen years old and when we visited his house, three months after he had passed away, his mother was inconsolable. His bereaving mother is barely able to talk amidst the sobs and hiccups. I sit there holding her hand silently for almost half an hour.

The counsellor is holding her head, wiping of her tears initially but later the nurse begins to console as we observe the visibly moist eyes of the counsellor. Meanwhile, the silence around us is infiltrated by her sobs. I get up to bring her a glass of water and after a few sips she shares that her son waited for our visits. Gradually, I muster the courage to ask about his final conversations with her, his last hours and his concerns regarding his own death. She tries to regain her composure and thus, begins our conversation. The team was visibly shaken especially the counsellor. She shares that seeing her,

> 'Youngest child die in front of her has been extremely difficult. This is a lifetime's grief; I feel the pain inside (indicating towards her chest).'

She remains silent for a long period bursting into tears often, reminiscing about him as well as sobbing silently. I sit in front of her, observing her and trying to be indifferent to the lump in my throat. She constantly says,

> 'I will not be able to forget him. Had God asked for someone else's life in my family it would have been less painful, he was the youngest and the wisest and may be that's why even God loved him'.

All, the above conversations may appear fluid but it depended on the use of a lot of non-verbal utterances to convey interest or impatience (after observing the team's reactions), the use or intolerance of brief silences so as to allow or interrupt the respondent to gather the respondents thoughts, as well as the use of interjections to shape the content and flow of conversation.

Anthropological research focuses on the mundane. But the contextual understanding of 'everyday' is relative. What seems 'ordinary' for someone living with cancer/loss or for those living with the person who has cancer can be very 'exquisite' for the researcher.

My aim, thus, was to make myself learn the ordinary from the perspective of those who live the very ‘ordinary’ as well as witness it around them. This process of learning is deliberate. The ‘ordinary’ acquires a different meaning in the lives of those who live the trauma of losing a loved one. When grief is explained as a social fact, many authors lay emphasis on its function of bringing an irreversible transition in the lives who suffer the loss. And since, the researcher is a positioned subject (Rosaldo, 1989), the present context within which the ‘mundane’ is explored is susceptible to either sensationalising or leads to a parochial/skewed understanding if the ethnographer categorically focusses on ‘grief’ instead of seeking a holistic observation. In order to avoid such a pitfall, during the interactions I tried to avoid a direct mention of grief and engage with cues about the life post-death with questions like; so what do you do these days to keep yourself busy, have you resumed job, how are you managing the family expenses, what is the source of income now, what do you feel after a year? etc.

Methodologically speaking, a delayed revisit to the field provided exploration of experiences of living with loss due to death in a much nuanced manner as the bereaving household had emerged from the initial shock and had been able to contemplate about the loss and a life without the deceased. The interactions in the field, therefore, incorporated the individual experiences embedded with a deeper understanding of the loss as well as a plan for the self and the family.[54] This account focussed on how the exercise was carried out given that the sociological and anthropological writings on grief and death focus

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[54] The post bereavement and grief theories in psychology and psychiatry often explicate the emotional stages to resolve the grief and letting go, which was the prerogative of the palliative care teams too (Howarth, 2007). But the sociological explorations illustrate the nature of continuing bonds despite the physical loss (ibid). In the above field findings, however, the grief is understood differently, it is more than an emotion of remorse with its varied manifestations and an elaborate analysis is beyond the limits and purpose of this paper.

extensively on the meaning, ritualistic explanations, management of the dying etc.[55] My dissatisfaction with the scant literature on a step by step exploration of grief within the two disciplines led to this write up which might suffer from a naively subjective reflexive bias but intends to provide an account of self-reflection as well as attempts to engage with what was often referred to as too morbid, depressing and difficult for comprehension based on the age[56] of the researcher. On one hand, many pioneers in ethnographic writing stress upon the role of self-whereas occasionally we get to see severe criticism of reflexivity. Patai (Pillow 2003) reflects, ‘At present, in my view, we are spending much too much time wading in the morass of our own positionings.’ Such distinct perspectives on reflexivity may baffle a beginner in the anthropological research, yet the ambiguity of the ‘how’ in the field does not sustain for long. The idea is to take a dive without worrying about the calculations.

The field reflects on the promises of palliative care but these are not exclusive solutions. With increasing awareness about palliative care, the institutions are proposing it as another specialty in hospitals. Gawande (2014) and Dr. Rajvanshi in their own understandings reflect upon the futility of such efforts at structural levels. These may appear as stopgap arrangements but a lasting provision calls for more empathic communication. The art of care is the art to communicate and a percipient realisation of our own endings.

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[55] Read Clark (1993), Robben (2004), Kellehear (2009)

[56] During a few encounters in the field, I was perceived as someone too young to make sense of death and dying leading to no direct communication between me and the respondents. Many volunteers and staff members in the organisation felt the same and some of them later came to share that after observing me in the field they didn’t seen to think that way anymore.

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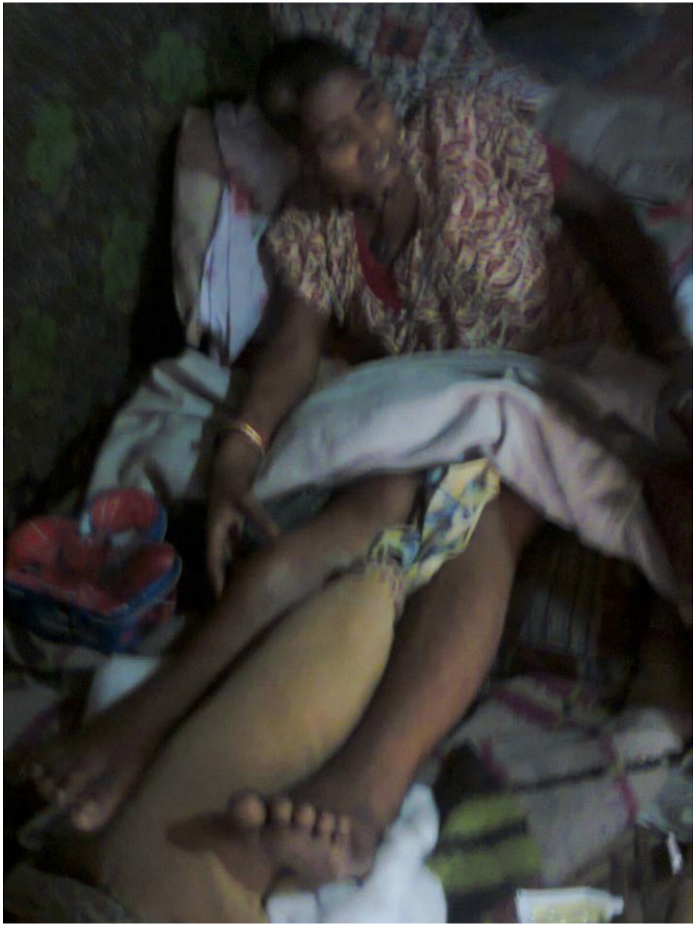
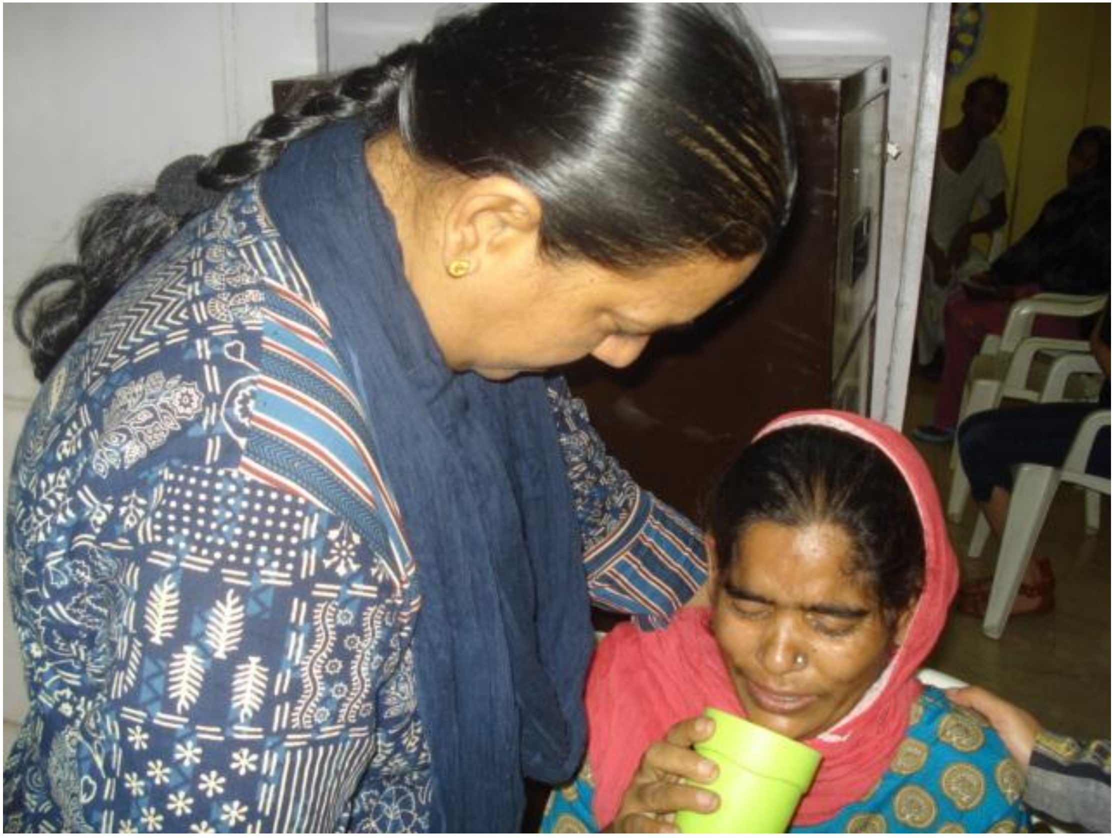
Appendix

Participants undergoing Counseller Training.

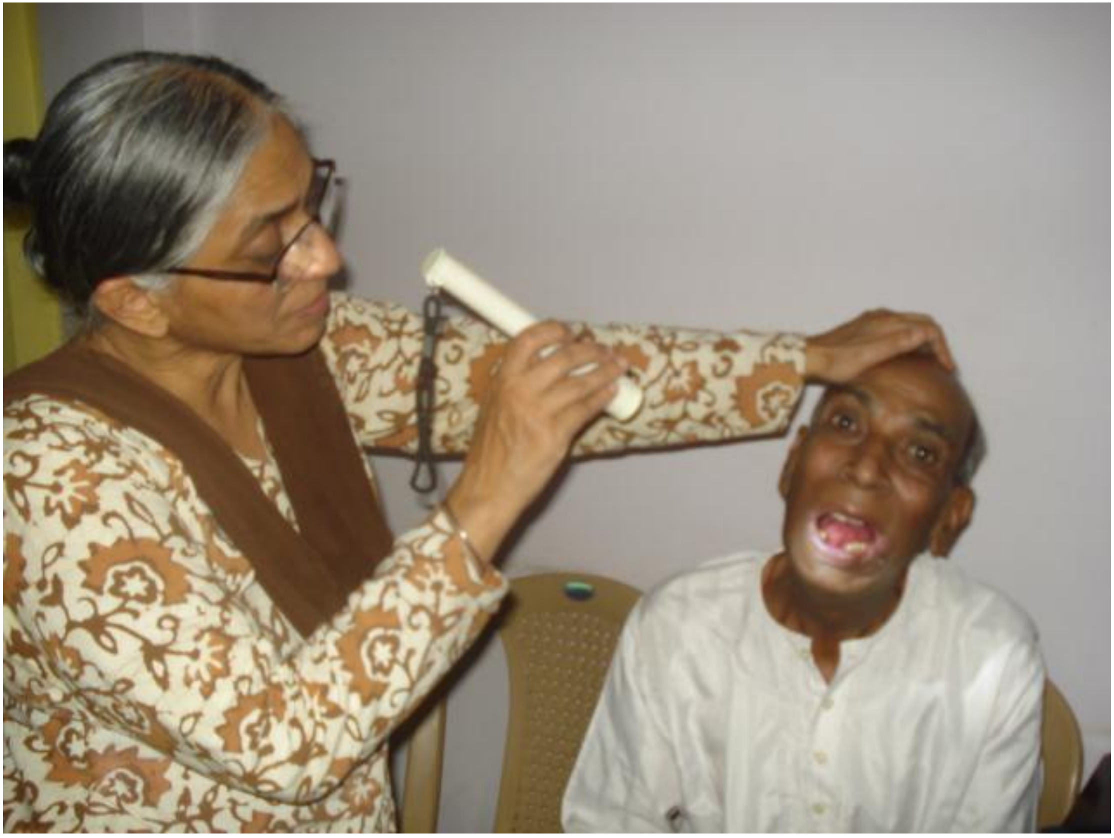
A bed ridden patient.



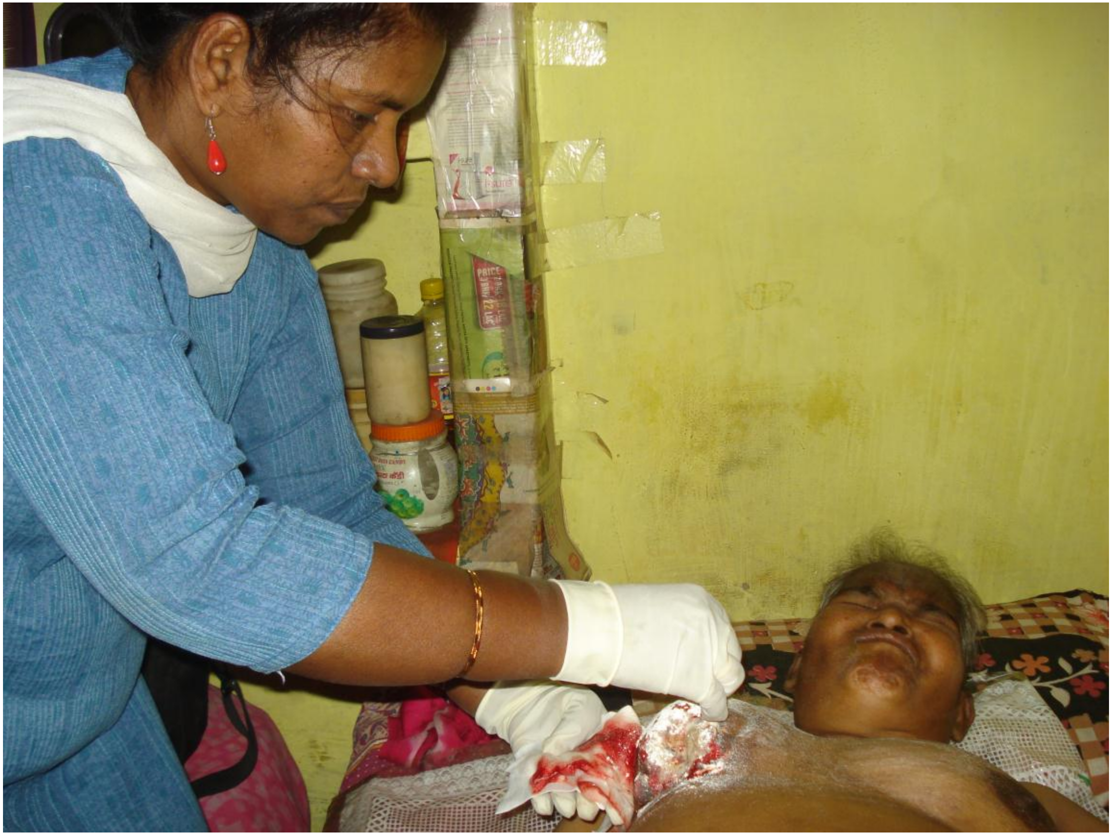
At the Out Patient Clinic- Counseller Supporting a Caregiver.



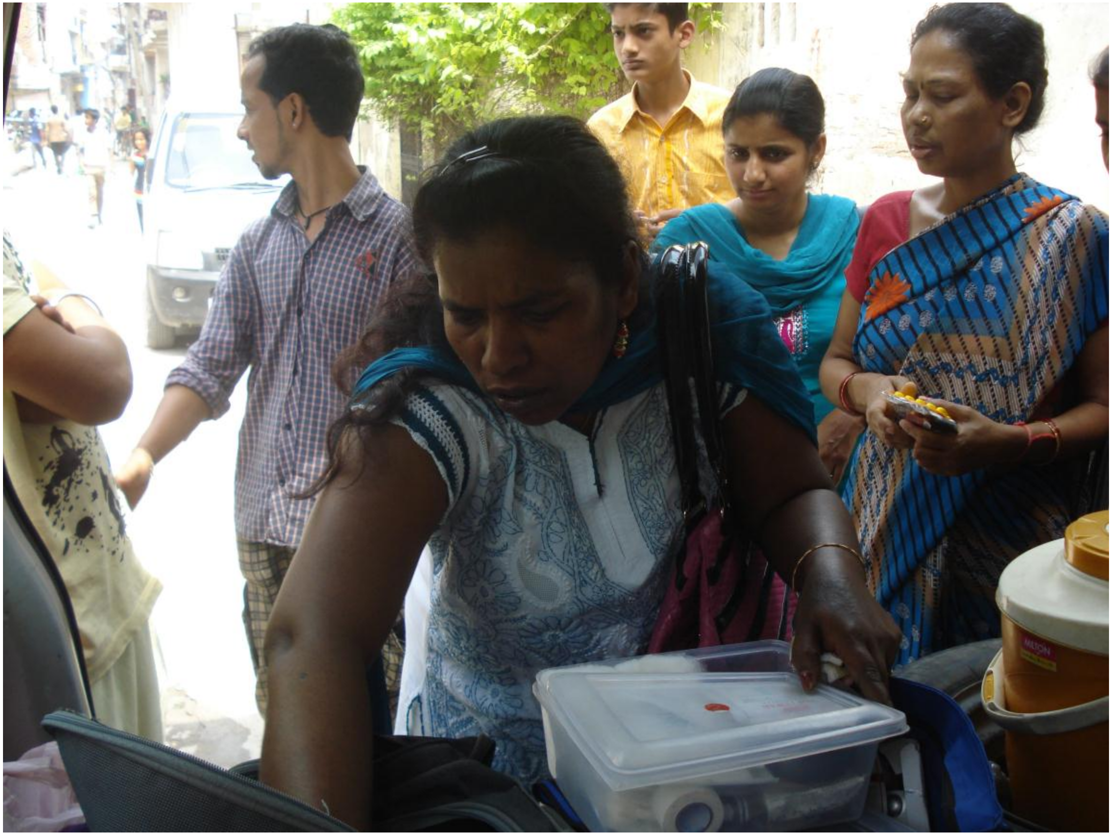
Doctor at The OPC(Out Patient Clinic)



A nurse during a field visit, dressing a fungiting wound.

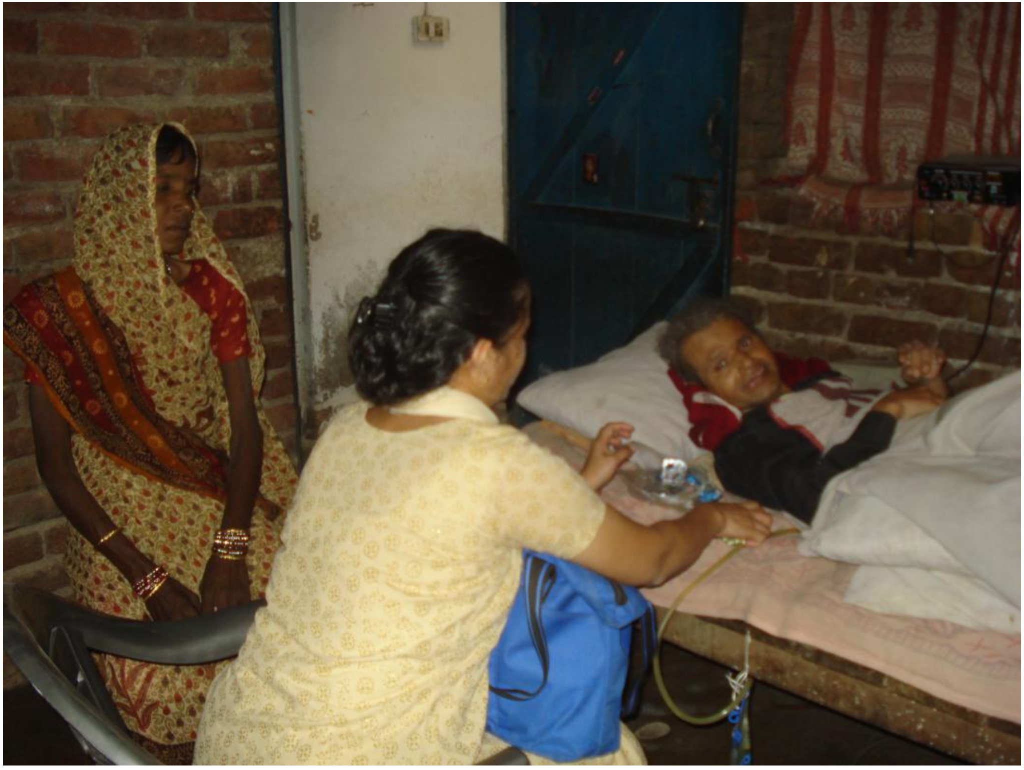


A nurse distributing medicines on field visit.



Interview with the patient.

A nurse observing the ailing patient as he is visited by a neighbor who suffers from Cancer. She is here to share her grief as her young brother had passed away a few days earlier.

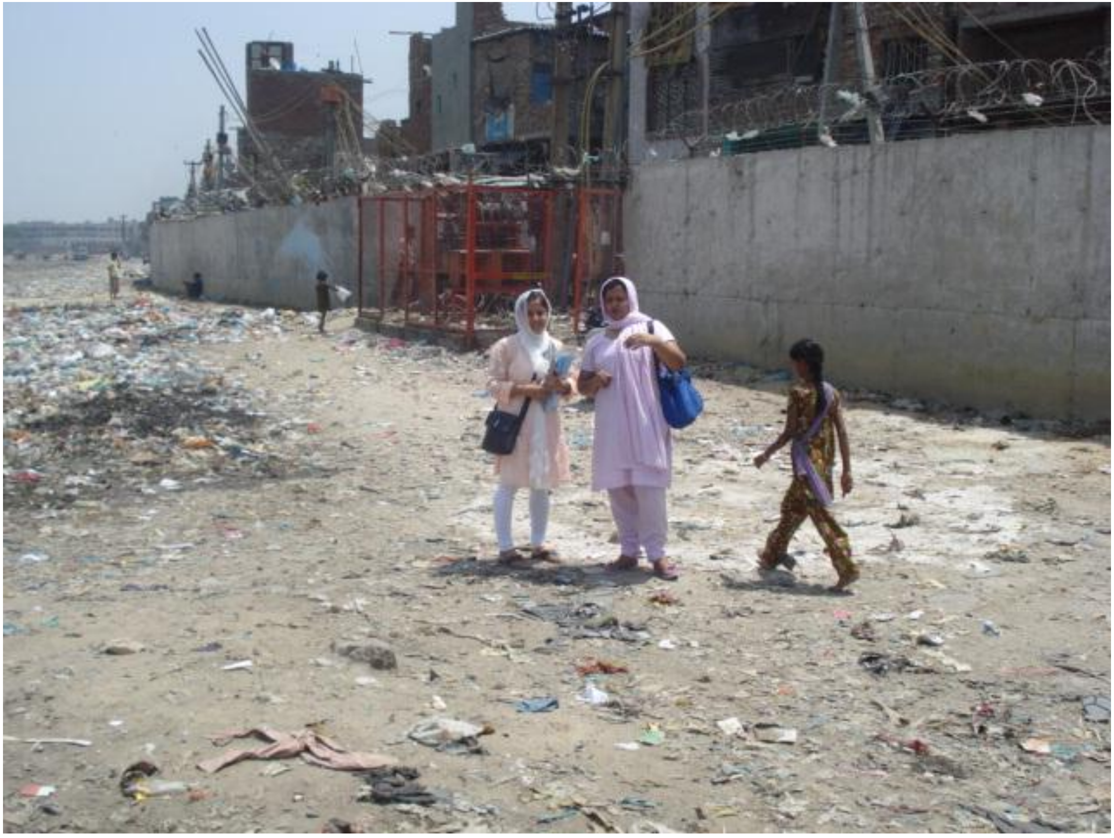


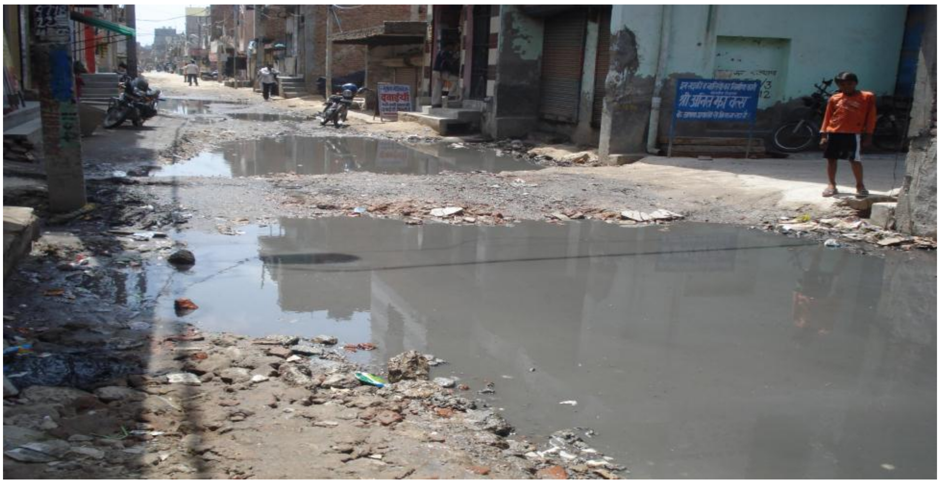
A patient with her husband

Patients at the Adult Day Care Group participating in Laughter Therapy.

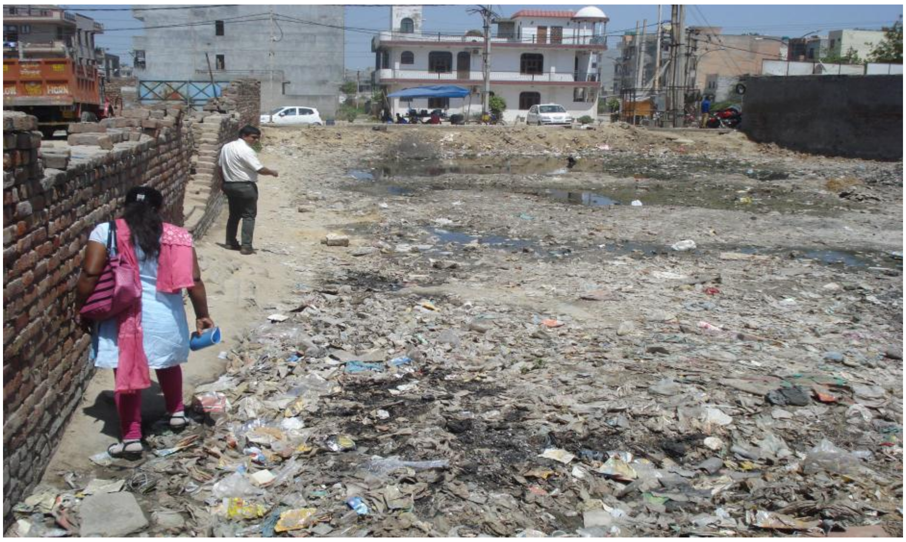
Children at the Day Care

On a way to the field.



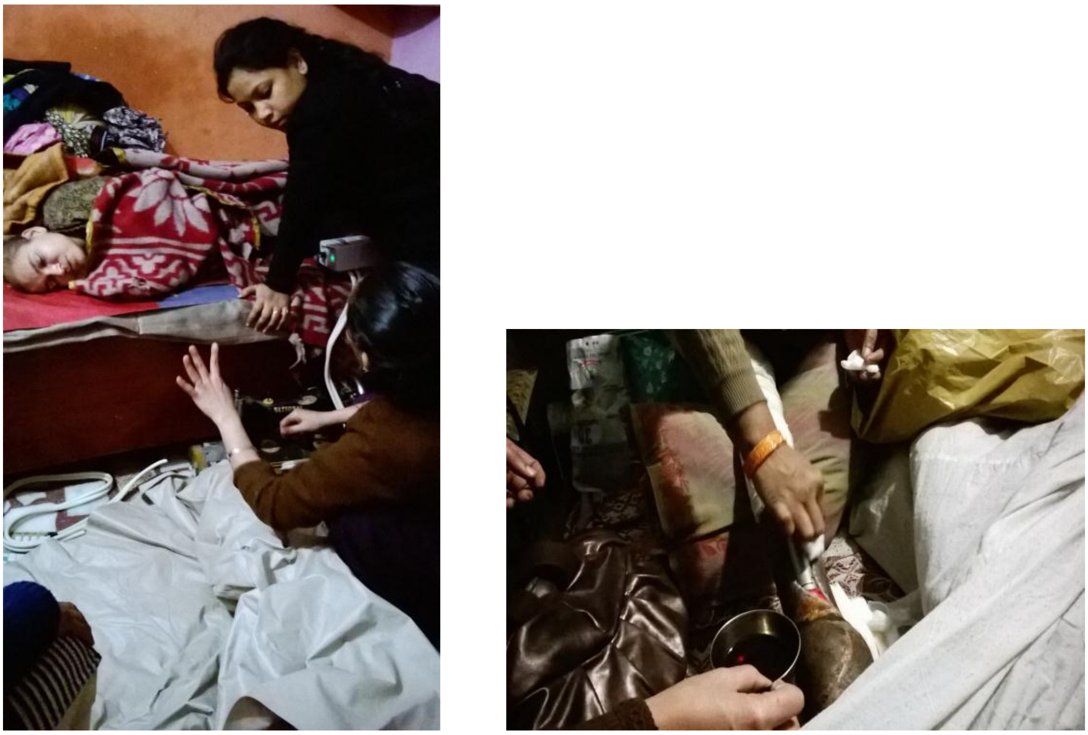


Way to the field visits.

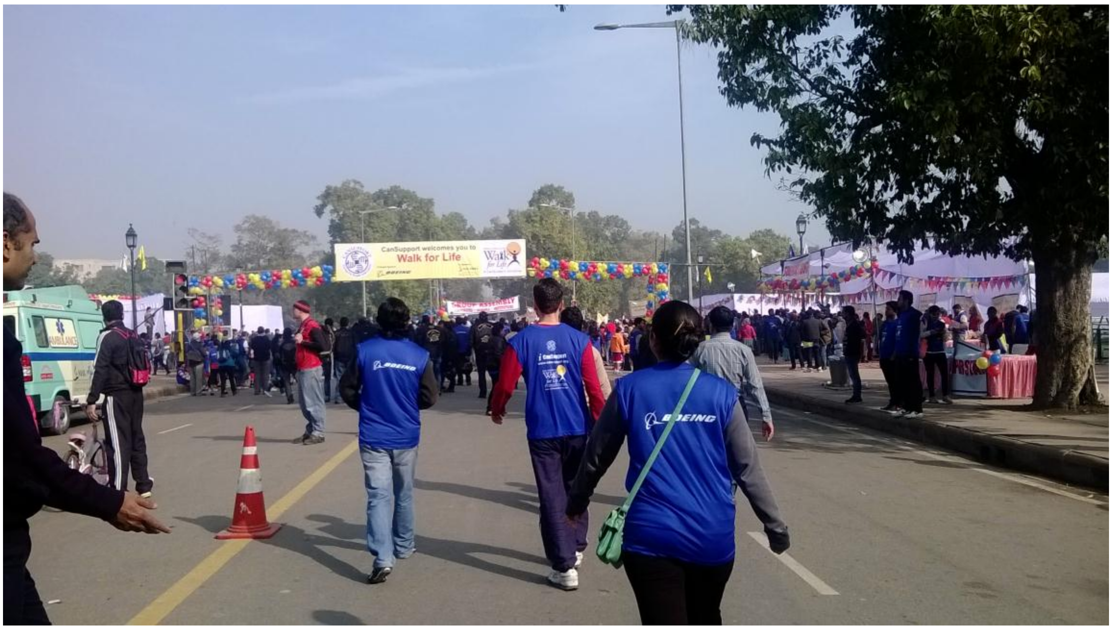


A movie outing with the staff members.

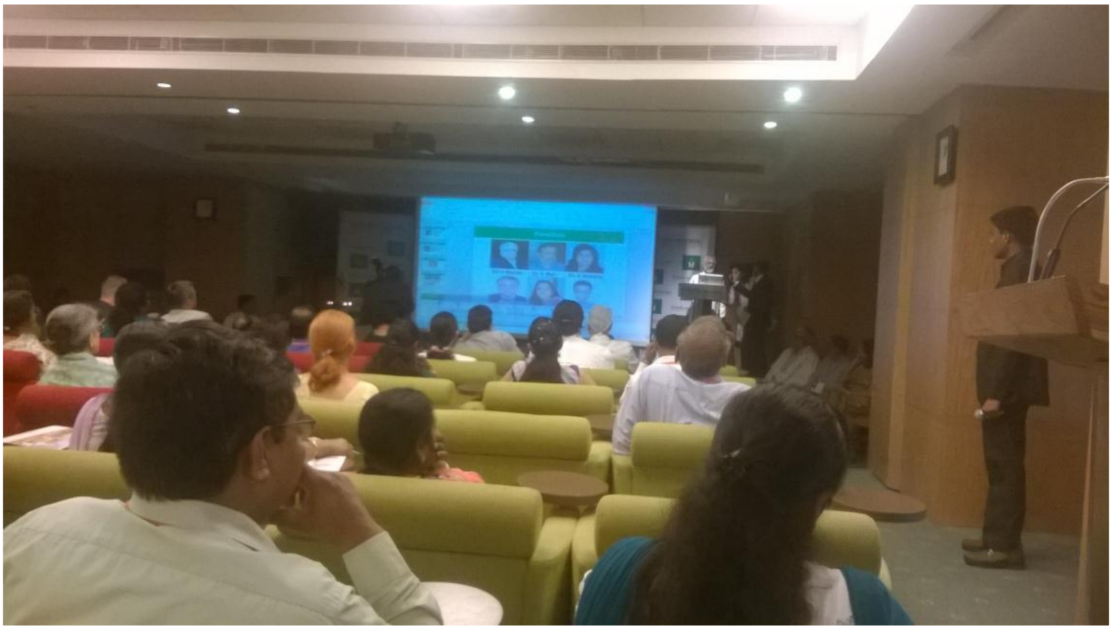
A nurse explaining to the families- with the air-mattress, and how to dress a wound, respectively.



Walk for Life



At one of the Conference.



Remembrance Day.