"Exploring the Growth of Care Industry in Urban India: A Case Study of Health Care Aides in Delhi"

Thesis Submitted to Jawaharlal Nehru University in fulfillment of the requirements for the award of the degree of

DOCTOR OF PHILOSOPHY

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CERTIFICATE

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DECLARATION

This is to certify that the dissertation entitled "Exploring the Growth of Care Industry in Urban India: A Case study of Health Care Aides in Delhi" is submitted for the award of the degree of Doctor of Philosophy of this University. This thesis has not been submitted for any other degree of this University or any other University and is my original work.

Ritumoni Das

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INTRODUCTION

Caring is an important phenomenon in human life and is needed by every human being at certain point. It is considered as the core of human values and rendered out of love. Caring is inherent in human beings and thus inevitably every human being is capable of caring. Caring can also be for the self where a person is supposed to take care of their own well being. The other kind of care is for sure when someone else is involved in care giving of a person. In this exchange process of care at various points, people perform the role of both care giver and care receiver. Caring for others may include a range of activities such as caring for adults, both able boiled and unwell, children carrying out household activities. In this case, caring may include numerous activities such as cooking cleaning, taking care of elderly, ailing. The focus of this study is primarily on the care givers providing this range of care.

Caring for others, elderly care, child care or caring for ailing has an emotional quotient and is labour of love. In this range of activities that required care, families play an important role. Historically, it is considered to be a natural process and a value of families to take care of children, ailing and elderly in order to manage their life. In this context, the type of support required for a child, elderly and an ailing person would also vary. Thus, one can discuss the concept of care for children in terms of bathing, feeding, taking care of their safety and adapting well with the society becomes the core. On the other hand, care for elderly would require helping them to cope with their frailty, providing them emotional support and taking care of them when they are unwell to cope up with their daily functions. The other kind of care is provided to terminally ill patients to cope with end of life situations and to perform their daily activities. There can be other scenarios as well when care from the family is important i.e is any kind of support required to receive to normalize life after hospitalization. As this providing of care is a common human value across the globe, India also has had similar values of families taking responsibilities of child, elderly, dying patients. Indeed in Indian society, taking care of elderly and ailing is regarded as a mandatory task for every family and often society frowns upon those who are not doing the same.

Traditionally apart from close members of family, extended family as well as the neighbourhood or community also have assisted in case of care required by an individual globally and also in Indian context. The community has played an important role in terms of care required to deal with end of life situations. Following from this, the whole concept of hospice care movement has been developed across different countries to deal with such need of long term care.

The hospice care movement discusses about building community networks through which systematic support can be provided to the patient and care givers. This concept of care-giving, both in the context of family and palliative care, by the community members builds on the idea that care giving is philanthropic and spiritual in nature. A wide network for hospice care was created for cancer patients both in developed and developing nations.

The need of support system for community has been also stressed in terms of care for elderly across countries giving rise to network of community care homes as a concept. The care homes are built to provide supportive environment, peer support and better care environment with the presence of care aides and clinical staff. In western context the development of care homes occurred earlier as the families started getting dispersed and there is a rapid growth of elderly population. In case of India, although aging is happening at a slower rate there is still a large segment of elderly and they again at times are being neglected by the families. The care homes fulfil this gap that exists in elderly care giving.

Despite the fact that the stake of community has been discussed over and over again and philanthropic and voluntary efforts have been created to cater the need of elderly and those who require long term care, the idea of family participation in care provisioning has remained at core for many years. However amongst the family members mostly it is women who had been responsible for most kind of care. Women had been necessarily taking care of children as mother and thus in many cases most of them end performing tasks of care giving in any situations in the family. Historically and traditionally women have been performing care work for elderly, sick and in any other care

situations. As women also have been performing other kinds of domestic responsibilities the boundaries are blurred between such work and care work.

Gradually women from higher and middle income groups withdrew from care work if not household responsibilities leaving a gap in societies for care providers. A section of women who could have access to education and economic resources had been out of home space to earn a living. The movement of women from their home to the market created a problem both in the arena of domestic work and care giving. There are other important phenomena as well which led to a care gap in the families. One of the most important reasons was expansion of urban centres, concentration of jobs in such spaces, long hours of work gradually leaving families without any support for care for short term and long term care. Apart from this, the community based initiative and networks created also started to dissolve gradually with an urban expansion. In Indian context as well there are growth of metro cities and a section of women having access to better education and economic opportunities moving out of household activities.

Thus in case of our country there is a change in family systems and with geographical distance between families there was a gap felt for immediate help and support. The access to extended families shrunk and also many of the families moved out of the country leaving their parents to stay back in the country. The impact of such change was felt in the care giving scenario as the number of people seeking short and long term care at home, or elderly leaving all alone did not decrease.

As the health sector saw the advent of globalisation and commercialisation the expenses increased and in fact to keep a patient in hospital for longer duration also had become an extravagant affair. Moreover home based care was indeed a necessity for terminally ill patients and could not be avoided. With this rising demand for a helping hand the health care industry also started building home care as a commercial product.

The primary stakeholders in creating a market around care to be provided at home were for -profit organisations in many of the countries. The private hospitals as well played an important role in provisioning of home care. At the same time the affordability power of the demand side has increased and hence there was also an acceptability of the growing care industry.

Although growth of home care industry took place both in developed and developing nations, the evolution has been different in both contexts. In certain cases the home care industry was also sponsored by government, which is in the case of National Health Program of United Kingdom, however in the countries where health care is being privatized widely the stakeholders are primarily the For-profit organizations and hospitals extending their branch for provisioning home based care for terminally ill patients, short term care for injury and surgery. Although as mentioned the home care provisioning in United Kingdom has been dealt by the National Health Service scheme, the ownership of private bodies have been increasing gradually. In fact a very high number of literatures available from USA indicate that the home health care is highly expensive and it is hardly covered by the social security systems. In many of the western countries, the agencies working for provisioning of care aides have designed modules and training guidelines for quality health care. The western countries also have prepared certified courses for home health aides for better professionalization of the workforce. However as far as the recruitment processes are concerned the care aides come from the lowest socio –economic order. The majority of the workforce is women and is Hispanic or black. The care work despite the attempt at professionalization is looked down upon as dirty work as it includes bathing and cleansing of an ailing person. Most of the workforce opts for such work owing to their socio economic position, migrant status and dire need of work. The availability of workforce in western context has also become possible owing to trade and tariff agreement that has enabled movement for domestic and health care worker including care aides from countries like Poland and India to other developed nations. The sections of migrant workers are often underpaid in these developed nations. Despite the fact that the care industry is drawing immense profit, the wage has remained an issue for home care aides. The genderised nature of paid care work also makes it low paid job as in many countries the wages for women are lower than men. The assumption of it being a low skilled work also makes it low paid in nature. In western context

like in USA however the wages can be little higher with unionizing of the health care aides. As the wages are low, the care aides in western context also end up working multiple shifts to manage the expenses in household. The condition is worse in case of self employed care aides which is also large in number owing to huge number of legal and illegal migration to developed world.

Apart from the issue of low wages there are other challenges faced by the health care aides in western context. Although a care aide in western context works in a team and is assisting the clinical nurses and the doctors visiting home, the burden of work majorly falls on health care aides. In many cases the care aides are working extra hours to ensure the patient is able to cope with daily activities of living. The burn out is often fatigue from working multiple shifts as care aides. The patients can be demanding and often out of emotional attachment as well the care aides work extra hours for each patient. The other challenge faced by the care aide is the search for dignity and respect in care work. Although in western context the agencies have been working in building trusts with the families and creating a team work between doctor, nurse, family and health care aide for providing home care, the respect for the work of health aide is never present. The work is considered dirty and most of the families refuse to trust the care aides. Cases have been mentioned in the studies where the care aides are often convicted of theft and other false accusation while working for a family. The issue of managing care in their own homes is also a challenge. As majority of the care aides are women and they also have their responsibilities of child, elderly or care for ailing at home. They are also not in a position financially to hire a care aide unlike the families they work for, creating an extra burden on them. The care aides often mentally withdraw or undergo massive emotional and physical stress because of the dual roles they have to play.

The industry has grown to a large extent in western nations and yet the condition of care aides is derogatory in nature. The nature and extent of the care industry is still in its nascent stage and hence it would be important to understand how the industry is ensuring care provisioning, welfare and wage issues of the care aides. There is also a need to understand if state plays any

role in wage regulation and other aspects of the industry which is also not vehemently present in western context. The presence of care aides for home based care is there in African countries with a very high rate of HIV / AIDS. Although the corporate and private sector is playing an important role, the Non Governmental organisations (NGOs) are also part of provisioning of such care in this context. The case of India can be very interesting to read when it comes to growth and expansion of home care industry. India also has undergone reforms and with post liberalization phase, the health care sector is increasingly becoming privatised. In this setting, the growth in urban centers are also adding to the clientele load for such private hospital, clinics and enterprises. As far as care work is concerned in Indian scenario, it is evident that an inequality exists and most of the burden falls on women. In recent times, however there is a migration of families both from higher and lower socio economic background to urban centers in India looking for better opportunities. As the family started to break up, a care gap also could be identified in Indian context. There are few observations such as India has 20% increase in elderly population and a huge number of deaths from cancer and HIV / AIDS. There is also high number of accidents leading to a need of short term care in certain cases. In this scenario, the need for post institutional care has increased owing to high expenses of curative care in private hospitals and long waiting hours at public hospitals.

The better economic opportunities whereas increased the financial strength of certain families, there were a section that were either underemployed or unemployed. This helped in both addressing the demand of those who could afford to pay and also create a supply chain of workforce with the groups under lower economic status. There is now a need to understand about the stakeholders who contributed to create a market in Indian context. In Indian scenario one can find the presence of a philanthropic hospice movement but the privatised industry of care is getting momentum owing to its marketing, easier source of accessibility and also it is demand driven and tries attending to every need of customer. Private enterprise is not oriented towards fulfilling the care gap in large way and is much more concentrating on creating it as a

profitable industry. Thus, the wage and welfare issues of the care aides also become a concern in Indian context.

As in India the majority of care and household related work is carried out by women, the genderisation is also evident in paid care work. A major portion of care workers are women from lower socio economic background replacing women in higher economic categories. As equitable wages is also a problem in Indian context and the care work is considered extremely low skilled job, the wages are much lower. Unlike in western context, the group of care aides are neither unionised nor do they work for a homogenous group. The number and nature of stakeholder contributing to growth of the industry in Indian context vary from NGOs, placement cells, private hospitals and international companies. There is no regulation except the minimum wages act which is followed by few of the stakeholders to settle the wage issues of care aides. In fact, there are no regulations to look into violence, universal standard of working for the care providing agencies. The issue of training is also at question as far as Indian scenario is concerned. The care aides are also not able to follow any standard job formats as they working with multiple kinds of organisation. The self employed care aides are completely out of any kind of benefits as they function on their own and have to resolve the issues of wages, leaves and working hours by themselves. The concept of paid care giving is also often confused with domestic work in Indian environment. The placement cells who are promoting care work and the self employed care aides who are often carrying out work both in the category of care giving and domestic work is contributing more to the confusion and haphazard nature of care industry in India. There has been regulation for domestic workers, but care work is hardly recognised as work in India. The reason for this is surely that there is not much organised efforts to include the workforce in the larger health sector although the need for paid care exists. Except few hospitals, there are not many who have recognised them as workers and in those as well they remain at the periphery. The other sort of care aides appointed by NGOs and placement cells never have been able to create a claim as health care worker as they remain away from the formal institution of health and works at home. Thus, the discussions on health care aide in India is still nonexistent although the

demand for such care aide is increasing and more and more number of organisations, placements cells, hospitals are entering into the market generating huge profits.

Keeping in mind that home care industry is still growing in the context of India and is very much part of drive to commercialise health care in India, there is a need to understand the nature and extent of this industry. It indulges a good number of populations both in demand and supply side but still remains unregulated and unorganised. Although there have been many discussions on the aspects of unpaid care work in Indian context as well the issue of women care aide working for low wages based on the concept of care being and emotional labour and to be provided as free service is not much discussed in literature. The welfare mechanisms for the care aides vary from one institution to other creating confusion and exploitation of one segment of care aides. As there have been no initiatives to work for the rights of the care aides, it is impacting largely the self appointed care aides. The study will explore into the perception of care aides and look for scope of regularising and professionalising the work of care aides. It will also look into challenges of the care aides, the difficulties they face to enter into a different household and of socio economic background both in the selection and significance treatment towards care aides. As India has been recently moving into a creation of a paid industry, the experiences of informal care aides will also be compared against the paid care aides to understand the level of exploitation, burn out issues in both categories.

Chapterisation plan

Chapter 1: A Review of Literature on Care situations, Commercialisation of Care

The first chapter includes review of literature on growth of care industry, the role various stakeholders as derived from various available studies. It looks at definition of care and its division into caring by self, caring by families and communities. The discussion moves into understanding the role of families and communities extensively to later establish a link between caring by external members of the society. The chapter looks into theoretical framework

of feminine nature of work, economic theories that looks at care and sociological construction of care. There is a section with a review on commercial nature of care and how industry is growing in western nations. It delves into issues faced by health care aides and the response of health care systems. The chapter then moves into looking at the growth of care industry in urban India and the feminine roots of care. The whole argument of movement of care from unpaid to paid in nature in India is supported here with theoretical framework that talks about feminine nature of care and labour issues in home health care work.

Chapter 2: Methodology

This chapter details the methodology adopted in the investigation. The chapter looks at conceptualisation of the study derived from the review of literature. This section builds a concept note on the nature of care, the role of society and the connection of issues such as gender, caste, and class to care work in the context of Indian cities. It gives an overview of the research questions and Delhi; the area of case study. It entails the nature of the study, which is descriptive, total sample size, rational and also the steps followed for data collection. It also gives an overview of the ethical ground that the researcher followed in the whole process

Chapter 3: Home Health Care Industry, Genesis, Stakeholders, Emerging Concepts, Market

This chapter is analysed based on website data of various companies, NGOs and training institutes providing home health care. Additionally there is also primary data to support the analysis on various types of home health care agencies. The chapter looks at a very important base of the whole home health care industry in India i.e the entire network. For this many websites were used to map and derive into few major typologies. The chapter also has detailed analysis on the terminologies used for the health care aide in India. There is an analysis of the methods of functioning, techniques for building and promoting this industry. This analysis a very important component as the home health care industry is very nascent in India in comparison to many other commercial health care sectors.(almost a decade old).

Chapte4: Position of Health Care Aides in Industry, Hierarchies, Placement Strategies.

This chapter looks at placement patterns for health care aides across various types of agencies providing home based health care. This also looks at supporting structures and if there is any hierarchy within the agencies. Significantly an attention is drawn into how this whole home health care workforce is built and what are the systems that support such agencies. In the chapter the researcher looks at issues of training and also how this whole home health care workforce is placed in the care economy.

Chapter 5: Socio-Economic Profile of Health Care Aide

This chapter looks at sociological, economic, demographic, and educational and work profile of health care aides and its connection to home care work. This is very essential to understand as reviews have already indicated how home health care work is considered a dirty indecemt work and carried forth by only a certain section of the societies in many countries. The issues of migration, disrespect, based on social and economic status need a deeper analysis in case of home health care industry. The researcher looks at all these aspects through an analysis of socio-economic and demographic characters of the health care aides. There is an analysis of gender based nature of home health care work and also its linkages to lower payment, unsuitable working conditions.

Chapter 6: An Analysis of Work Experiences of Being a Health Care aide

In this chapter the researcher looks at a very important component in the entire ambit of home health care work, which is often neglected by the employer and families that opt for services of home health care aides. In the review chapter there is already a discussion around the emotional nature of home health care and the issues of burn out for such workforce. There are other concerns such as autonomy in care giving, support systems in dealing with patients come as major obstacles for this health care aides. The researcher analyses the issues of emotional and physical fatigue in this chapter also keeping in mind the dual burden of care for female health care aides.

Chapter 7: Discussion and Conclusion

The researcher looks at the major findings from the study in this chapter. These are analysed through a theoretical framework of feminism, labour economy and also sociological construct of care. Significantly there is in depth discussion of commercial growth of home health care industry and its implication to public health system. The other aspect that is analysed in this section is the condition of health care aide workers and their place in health care economy. In this section the researcher looks at issues of health care workforce and lack of attention paid to palliative care, post hospitalisation care and care for elderly. There is an analysis on how these issues are often neglected by health service systems and thus the new emergent categories of health care aides governed by the private bodies often face massive challenges to ensure welfare of their clients. There is a detailed discussion on its implication to crunch in human resources, migration of a workforce for care work and how this all is creating problems for creating better health options for people in India.

Chapter 1

A Review of Literature on Care situations,

Commercialisation of Care

The Chapter focuses on the important aspect of understanding what Care entails while reviewing the transition map of care giving from unpaid work to an industry. This review looks at studies that discuss various kinds of care. This is juxtaposed with an understanding of who provides this kind of care; be it role of families, community and institution. The chapter further analyses if care in families is gender sensitive. The review also looks at the transition from such traditional ways of care giving to the creation of an industry and also how a gap in Care giving came about by the gradual withdrawal of family and community from care giving. These sections on types of care, role of family members and women are analysed both in global context and the practices in India which is the basis of the study. The secondary review also dives deeper into how and when the transition from unpaid to paid care work took place with a change in family structures, urbanisation and newer economic opportunities for a section of women leaving a care gap in families. The evolution of paid care work in terms of typologies, issues at work, socio -economic background of the care givers, are assessed in western context which took place earlier than in Indian scenario. This frame of reference is used to understand the evolution of care industry in India which although is nascent, the presence of same is undeniable. Within this the feminised context in paid care work has also been examined.

1. Definition in Care

Care is defined as a personal connect with another person. It has been defined as a labour of love in which private or intimate activity is performed in a particular emotional state (Tronto, 2005, p.8). Franseca Cancian (Tronto, 2005, p. 8) defines care in terms of feelings and affection:

"My working definition of care is a combination of feelings of affection and responsibility with actions that provide for an individual's personal needs or well being in a face- to – face interaction."

As indicated in the above definition, caring is an activity which takes place only when there is a physical presence of persons, both at giving and receiving end respectively. However some refute this idea and state that caring cannot be only defined in the context of face-to-face interaction (Tronto, 2005). Tronto (2005) argues that caring can be understood in certain stages that can be categorized as, caring-about, care-giving, and care-receiving. Caringabout involves the need for care in the very first place, care-giving involves the process of assumptions of responsibility for the caring work and finally care-giving is the actual work of care, while care-receiving is the response to thing or a person who is cared for. Secondly, care is also defined in relation to caring for self and others, the first being psychological in nature, and latter being considered as a norm of the society. The third, "caring for others" defined as caring about the world, which is political and economic in nature (Tronto, 2005). Caring thus has different perspectives in different contexts as care for self comes as a need from mind, whereas, the care for others comes as a societal responsibility, for example, caring for children by mothers comes as a defined responsibility from the society.

Care is also divided as spontaneous care, necessary care and personal service (Hamington & Miller, 2005). This distinction is, primarily, rising out of looking at care as a work that is not necessarily provided by family members. Spontaneous care is defined as Samaritan act which is extended out of good will. The second is necessary care in which the recipient is only able to receive it from an expert, for example, care which is provided by a doctor (Hamington & Miller. 2005). The last category of care is defined more as a service rather than an act of care provided by family members or the kind of care which needs expertise. It refers to those acts which can be carried out by family members but is conducted by an outsider as an act of service, for example, taking care of a child is an act of care normally conducted by parents but it can also be carried out by someone else (Hamignton & Miller, 2005).

In this chapter, caring will be defined in terms of an activity which takes place through an interaction. As literature indicates care is a phenomenon carried forth by family members, external persons and institutions the chapter will entail the nature of care in these contexts and how they are different from each other in the context of value.

1.1 Caring for Self

Caring for self has remained a dominant aspect of care giving. It has been considered as a key component of well being and road to recovery in post 19th and 20th century. This era was one where self medication and self care was considered unhealthy with developments in medicines and clinical aspect (www.wsmi.org) .However with the changing scenario and more cases of noncommunicable and lifestyle diseases self care is found to be an important aspect of care. Self care can be defined as practices in broader context that individuals perform on their own (http://www.improvingchroniccare.org). Therapeutic care is considered as sub concept itself which entails knowledge and skills needed to support self care practices are self-monitoring and symptom management, including monitoring of specific physiologic parameters or symptoms of a health condition; adjustment to activities of daily living, seeking care as needed, and participating in treatment. The domains of therapeutic self-care activities include client's knowledge of prescribed medicines and treatment, ability to recognise signs and symptoms and knowledge related to action during emergency (Mishra et al 2013). Self care management has become an important component in caring paradigm self management is seen as one of the important component of human well-being. Self care management in the context of India also has seen recognition in the context lifestyle disease such as diabetes (Mishra, et al, 2013). Although many of the research studies have identified the need of self management in such life style diseases study further shows that a number of population across globe are unable to opt for such care process designs due to lack of information available (Mishra et al, 2013)

1.2 Caring by Family

Family members are recognised as the mainstay of community care for frailing and older people. Self care although comes as a necessary concern and very important part of well Admission to an aged care facility ushers in care by others, though social workers and others assert families continue to contribute in a significant way.

As discussed in Abel (1986) caring for others imply the support needed by the disabled and elderly. The caring perspective is most importantly long term activity. The nature of care work is intensive as it needs a person to give constant attention to the one who needs care (Porter, 1986). The family plays the most crucial role in providing care. Indeed 80% of the care is provided by the family members (Abel, 1986, p. 481).

Caring by family also comes as a value in specifically in the Indian context. As indicated in one of studies, family is considered core of care giving when it comes to the elderly in the family. There is a more amount of dependency for care giving on family members in Indian context (Brinda et al 2014). The study further adds that a cultural norm dictates such behaviour in Indian communities.

Women within the boundaries of household are entrusted with all responsibilities of care giving right from care giving to a child, taking care of needs of the family, husband, elderly and those who have fallen sick. But all these come as natural obligation for her without addressing the capabilities. Most importantly she lacks freedom to express emotions and to refuse to care for someone in the family. The paid care giving process also needs to be reviewed in the context of subjugation of women where she lacks freedom to express; her well-being is also not given attention. The issues of paid caregivers often do not attain attention as an employment for woman is hardly an entitlement and secondly a woman doesn't automatically hold any right for equal treatment as an employee like their male counterparts.

It is often argued that women are the nurturers and carers of the society and hence would be best suited for caring activities. Care is often explained as a feminine trait as opposed to a masculine one. A masculine trait is to act as a bread winner and look after monetary issues of the household (WIDE, 2009). A set of literature focuses on social construction of care and how women are put into core of care giving. This section of literature deals with and interrogates how care reinforces inequality in terms of gender, race, ethnicity (Misra, 2003). The women are considered to be naturally willing to take care of children, ailing and elderly, as caring is assumed to be an inherent trait of women. She uses caring as an opportunity to socialise. However, feminist literature has refuted the idea that women want to be in care paradigm. This is argued to be a responsibility often carried out by women out of social pressure (Porter, 19 86). It is extremely distressing for a woman to take care of her ailing husband who is incapable of even using lavatory on his own. Moreover, it adds up to the work of a woman if she is taking care of a toddler alongside (Porter, 1986). Care-giving is a kind of labour around which a woman has to organise her life. Indeed, for care giving it becomes crucial for women to leave their jobs to follow the schedule (Misra, 2003).

"It is a specific kind of labour that women perform that requires women to constantly organize and arrange their lives to meet the needs of others ... A life-defining phenomenon in women's existence and a medium through which women are accepted into and feel that they belong in the social world".(Misra,2003,p389)

The role of women, thus, has been made central to care-giving in society. The recent feminist literature has highlighted women's massive role in care-giving process to terminally ill, which is informal and unpaid in nature (WIDE, 2009). The role of women has always been emphasised as carers and nurturers in the society, and caring is a natural activity which is done out of emotional attachment to family members. (Valles, 1998)

The studies, which have analysed the labour of women, reveal that it has a good monetized value, which is often ignored in the pretext of it being a compulsory social role. In their study conducted in Africa, they have created an exercise to monetize the value of the invisible, unpaid work women often do as social responsibilities (annexure 3 cost of care work). Similarly, there

have been other studies conducted in Africa which reiterate that women are spending major portion of their day carrying out unpaid household tasks without any support from their male counterparts (http://www.actionaid.org). It indicates the fact that women often find such work extremely demanding and stressful. As is stated by a woman in the same report

"This [unpaid care work] is the type of work where we do not earn money but do not have free time either. Our work is not seen but we are not free as well." Woman in Patharkot, Nepa (http://www.actionaid.org, p6)

It has been argued in one of the reports of the United Nations that the care work indicates an immense amount of gender inequality. It has been considered an issue of human rights and that most burden of care work which is undervalued falls on women. This consumes maximum energy and time for women who otherwise would have been able to engage in productive work (http://www.ids.ac.uk). It further highlight that the non-monetized nature of such care work is pushing the female gender to poverty. It estimates that the monetary value of unpaid work carried out by women would constitute 10-39% of the GDP (http://www.ids.ac.uk)

A study conducted for Australia and Canada also discusses the undervaluing of women's work. Illustrating the argument, the study adds that there has been an increasing level of women's participation in the wage work with a sharp decline in remuneration (Stewart, 2013). The gender inequality also needs to be understood in the context of freedom and rights.

In Indian context literature further states that women in Indian are carrying multiple burden of care work. Women in Indian situation by default play the role of care givers (Sharma et al 2016). Further many other studies also argue that with growing nuclear families indeed the kind of care giving has become a more difficult task, with both spouses working many a time the burden of caring of parents, in laws yet falls on women making it difficult for them to cope up with their work and duty as care giver (http://www.womensweb.in). The men in this case mostly act to bring income or any external article required by the patient (http://www.womensweb.in).

Sharma et al (2016) also has identified care burden on women for specialised care. They have examined gender differences among family-caregivers of people with mental illnesses, have concluded that women spend more time in providing care and carry out personal-care tasks more often than men. These studies have also found that women experience greater mental and physical strain, greater caregiver-burden, and higher levels of psychological distress while providing care. However, almost an equal number of studies have not found any differences between men and women on these aspects.

1.3 Caring by community

Thus the definition of care itself highlights care as an intimate activity requiring constant attention and generally preferred to be performed by the family members. However it also brings into notice the fact that care can also be provided by an external members as well. The traditional definition of care as one of the options and mostly talks of does not include paid care work care being philanthropic and value based in nature. In this case the component of palliative and elderly care has been discussed in length analyzing the components of such care and the role of care aides. The literature on palliative and elderly care has narrated the care giving process as complicated in nature and that it is much more beyond just helping a person to tackle daily functions. This explains how palliative care can be burdensome and exhaustive in nature for the care givers which will help in linking it to burn out issues of paid care workers . This includes the need of involvement of care aide, family and clinical staff for efficient care provisioning at home. This is important to discuss here as it will be reflected in the later section of the review how care aides feels overburdened and without any support system owing to passing of all the work to them by family and community. This also talks about how providing end of life care is a concept that requires training for the care aides which can also be linked to the issue of lack of training on the part of care aides specifically in developing nations.

The concept of care giving for dying requires a differential approach than clinical. Most importantly one needs to understand the importance of home and family in the context of long term care giving. Home is the preferred place

for dying for palliative care patient. Whereas caring for patients at home are much of significance in long term care, the same becomes excessively burdensome for the family members. Symptom management for dying at home can take a toll on the family members and there are high chances of them confronting emotional burnout in the process. As argued in Hassan, 2014, the family members of the patients seeking palliative care lack knowledge and hence undergo burn out while taking care of patients. To give palliative care one requires empirical knowledge, henceforth the whole paradigm of palliative care needs to involve skilled set of workers. Pre-death care is sought at home, hospitals and hospice care centres. The process needs to be understood through an analysis of need for palliative care, pain management process and planning for emotional well being of the patient and the family (Ferris et al, 2002).

"Physical, psychological, social, spiritual and practical support to people living with life threatening illness and to their loved ones. Care teams include physicians, volunteers, nurses, spiritual counsellors, friends and family. It can be provided, at home, in hospitals, nursing homes or free-standing hospice facilities" (Ferris et al, 2002, p17)

As depicted by literature on palliative care physical and cognitive function gets highly affected in case of elderly population. The physical fragile state demands much more assistance and consolidated efforts. This is the stage when the patient is being prepared for death. A study suggests that the experience is much graver in case of women and those who are suffering from chronic illnesses. Scales of measurement is often used for understanding cognitive disabilities amongst old. These are free recall technique where the respondents were given words and asked to recall the same after five minutes and the numbers of words correctly pronounced were counted. Apart from words, knowledge of measurement, orientation of language etc were also included in the methodology of checking cognitive functions.

As one discusses about the complications faced by the patients making long term care giving a difficult process there is also a need to understand the need of care for short term emergencies i.e injuries and post surgical recovery. Short term care is also an important component in which the care givers need to focus on providing assistance for activities of daily living. The short term care is more complicated as the duration is short and the patient requires restoration to normal as early as possible. Short term care in clinical terminology implies care needed for a short term period and such care would require a person to stay for a short term at rehabilitation home which can help them achieve a maximum stage of restoration. This generally includes physiotherapy, physical action and at times counselling services. This includes a process in which the rehabilitation facilities also extend these services to their home with participation of nursing assistant, physiotherapist, counsellor and home care aides (http://www.fiftyplusadvocate.com/archives/4038). This practice can last for six weeks. Although the short term care is not a long process, the burden of caregivers in such situation is also immense as attaining maximum stage of restoration in a short span of time is much more a complicated process

1.3.1: Hospice care movement

One of the most important aspects in provisioning of palliative care is growth of hospice movement, which pays attention to such care with a spiritual outlook. The core belief is that the values such as genuineness and compassion are primary in palliative care, rather than professional practices of counselling. The content of palliative care finds its presence in the philosophical discussion related to need of healing rather than any medicinal treatment. The ground of such care is to help a patient deal with anxiety and pain related to death. The hospice care is again a process which in its inception is considered needed for establishing reciprocity between life and death (Russ, 2005). The hospice care diverts attention from "hospital centric cure model" based on technologies to comfort and quality of life for a dying person. The hospice movement that started in Western countries had focussed on space, where a healing with philosophical outlook could be achieved. "Acceptance" of death might be reached, and the healing and work necessary for a "good" or "gentler" dying is conducted (Russ, 2005).

The hospice care movement which came into being in USA in 1969 based its premise on love and care (Russ, 2005). Indeed, the hospice movement was important in bringing out caring aspect to community from family. The movement, initially, was not focused entirely on profit motive and had philosophical underpinnings. Hospice care, however, became an important development towards creating institutional arrangement for dying patients where his or her specific needs for coping with death were to be taken care of. The movement is a process of protecting dignity of terminally ill patients and keep them an active participant of society till they die (Chaubey & Aarti, 1999). The movement has also been about preparing the family of terminally ill to accept death as a normal process and that it should not be hastened or delayed (Chaubey and Aarti, 1999). The movement to indulge community and voluntary efforts was only restricted to developed nations and its presence could also be found in the Developing world.

The community model of care giving or informal care giving finds an important space in literature of many countries. As suggested by a study the latino American countries have the cultural notion of taking care of elderly in providing comfort at the end of life. Indeed also in the context of developing nations such as South Africa and India with rise of diseases like cancer and HIV/ AIDS hospice care movements have found its space. In Indian context there are indications of hospice care moving out of the realm of households (Seamark, 2000). The hospice movement and the growth of missionary organisation that emphasises on home based care indicate community engagement in providing care (Seamark, 2000). The palliative care movement in Kerala was founded on similar notes to that of western countries, which is to improve quality of life by reducing suffering and pain of the patient and family (Abraham, 2013). The palliative care network in Kerala was built on voluntary efforts from the community members to help these patients cope with life threatening diseases (Abraham, 2013). In the context of Kerala the hospice care movement has expanded a little more from the urban cities with neighbourhood network models. The neighbourhood network models are to create sustainable community based palliative care networks (Kumar & Numpeli, 2005). It is built on the idea of community based responsibility for

their own palliative care. In such networks, the volunteers from the community themselves identify the chronically ill patients of their community and intervene for long term care, along with the specialised health care work force (Kumar and Numpeli, 2005). These neighbourhood networks of Kerala also have major contributions from religious groups in its over-all functioning. The Mujahid Muslim Organisation has played a crucial role in setting up clinics in few of the Districts of Kerala. Apart from the Muslim organisation, there are Christian missionaries who also play an important part in palliative care networks (Sallnow & Chenganakkattil, 2005). In addition to the institutional delivery by the Church, there are nuns who volunteer as independent care-givers in clinics (Sallnow & Chenganakkattil, 2005).

Despite the fact that hospice movement initiated its journey with a philanthropic underpinning it also went through change in recent times. The movement which puts emphasis on care and love as core philosophies earlier depended on voluntary engagements from the community (Russ, 2005). Here, the funding also had largely depended on charity sources. However, as care industry has become much more marketised, hospice movement has not restricted itself to love and care, and has moved towards earning profit, which, today, plays an important role. As is argued in recent times, the hospice care work intersects between two different types of economies in which one is characterised by ethics of pure gift, sacrifice and charity and the other with efficiency, discipline, cost containment and profit making (Russ, 2005). A set of organisations working in hospice care have given utmost importance to quality assurance and selling the best sort of hospice care package as a product (Murray, Sheikh and Lynn, 2008).

2. The Transition in Care from Informal to Formal

The transition from informal to formal care was dependent on many developments, primary being change in family structures, and change of role for women. It is important to understand how and why the role of women changed from household activities to wage earning. One of the reasons was movements of families to more expensive urban centers and more accessibility to resources for certain section of women leading to their engagement outside

home. In this case in certain countries the welfare state played a role to encourage women to undertake activities that paid regular wages. One of the arguments is that the State can bring equality by introducing reforms to involve women in wage work diverting them from performing unpaid labour in the households (Little, 2005). The Welfare State in western context has adopted reforms where women are trained and encouraged to be involved in wage work to bring equality (Little, 2005). With such movement women being indulged in work outside home gradually withdrew from care work leaving a gap in the system.

Apart from this the transition from informal to formal care giving for long term care is also dependent on the factors of individual choice, absolute absence of social support system and also the ability to afford care. Social support is an important indicator in defining whereas one opts for formal or informal care giver. It implies if the ailing person can be supported by any relative, spouse or any other person who can ensure living arrangements. The transition of care giving from informal to paid become easier for people who were financially much more stronger. The decision for formal or informal care giving is also governed by the ability to purchase care for a person. The insurance coverage in the context of many countries plays an important role. The families often opt for paid formal care giving if the insurance process covers the expenditure.

Following from the theory on feminised nature of labour there is a discussion around how economic theories perceive care. The conventional economic theories and how they define masculine labour is discussed in a study by Marzurkiewicz (2007).

Mazurkiewicz(2007) has shared how the present construction of care work is actually rooted in history and development in economics. Further adding to this it is showed how labour economics have defined women as not part of productive economy. As informed by Folbre (1991) by 19th century the women were considered as dependents. This was a result of change in economic production and perception of neo-classical theories that women hardly could be part of economic systems with the advent of industrialisation.

The whole conceptualisation of care actually intimidates the basis of classical economic theory which does not recognise the need to discuss people's welfare as indicated by Folbre (1991). Thus the one who discusses care having economic value actually proposes to follow alternative school of thoughts that links economics of care to feminist theories.

The Institutionalist (Chavance, 2009), an alternative school of thought discusses care as social activity and recognises gender norms as important institution in the economics. The core of the argument for this school is importance of socialisation in building of economic system and how it is not a matter of an individual and also can include cultural norms.

Another belief shared by Institutionalists and Feminists is the significance of power relations and conflicts in the economy. Institutionalists have used the concept of power through multifaceted systems of status and hierarchy (Waller and Jennings 1990). Feminists use the concept of power and subordination to describe gender relations in economy. Concept of gender is seen as a system of power which brings feminist theory and institutional economics together (Jenings, Waller 1990). The system of gender seeing as power indeed brings the feminist perspective of care and institutional economics together. This theory is very important when it comes to the present study to understand care work's transition from unpaid to pay and also how it has still remained feminine in nature.

The other theories that are useful in understanding the concepts of care is the connotation of decent work which is used to understand the working condition of health care aide. This terminology coined by ILO (www.ilo.org) implies aspiration of people for fair and productive work, security in workplace, better development of self and families. This can be correlated with the experience of health care aides on lower respect paid to health care aides and how their work has limited growth as a career, analysed in the section on working condition below. This study also elaborates how the narratives of health care aide leads towards an understanding that home health care work is considered undignified.

3. Creation of a Global Home Health Care Industry

The care work perspective needs to be discussed as a marketable product. This has been possible because of the demand put forth by the families who are seeing a care gap and can afford to purchase care. Secondly, an environment for business has been created with many stakeholders, such as private, public, NGOs and companies participating in provisioning of the same. The role of supply side is indeed important to assess while studying the growth of Care industry.

The private hospitals and institutions are not only limited to providing institutional care but they have extended their role to provisioning of the home based palliative and short term care as well. Many of the western countries has developed models of training and creating certified programs for such home based health care industry. These training manuals have created the type of job responsibilities and have also discussed in detail the qualities of good and efficient care givers. These programs and training manuals work as guidelines for care provided at home which is beyond hospital (Green, 1996).

The care-giving process becoming a market product also has been possible due to the availability of such workforce, who is willing to work as caregivers. As is indicated in literature, this has also been possible in western context with many Hispanic and black women being available for such roles (Annexure 1). A large section of women from such background come into care work owing to economic hardship (Stacey, 2006). Apart from this, a majority of population who opt for such occupation are of migrant status and are in dire need of work (WIDE, 2005). Ironically as discussed above the shifting of one section of women for better paid job created this space which was filled by women belonging to lower economic sections.

The growth in such a care workforce is not only confined to developed world and such markets are also available in developing nations where issues of poverty and migration prevail. In South African context, it is the experience of HIV/AIDS, the apartheid had created a disruption in the family, and hence the need of organising care giving from outside the family rose (WIDE, 2009). This labour force has been made available through NGOs, hospitals and

placement cells (Annexure 2). In many cases they are also independent care givers who are self-employed.

The availability of workforce also has become possible in many of the countries in post liberalisation phase (Annexure 3). The international migration is often considered the solution to short supply of workforce in many of the countries such as USA, UK whereas; the outward movement has come as a challenge for countries like Poland and India (Buchan, 2000). The globalisation phase has led to creation of bilateral and multilateral agreements between countries enabling investment to flow from one country to another. WTO agreement has created space for countries to interact with each The other in terms of patent, copyright and trademark law (Sykes, 2008). The General Agreement on trade and services came up in Uruguye round which was in response to growth in service economy which accounts for 60% of global output, 30% of the employment and nearly 20% of the global trade (http://www.migrationdrc.org). The mode 4 of the agreement has enabled the temporary movement of labour force which is identified by the agreements made between the countries and varies from few months to few years (http://www.migrationdrc.org). As the developed nations are undergoing problems of scarcity of labour owing to the increasing number of aged population, the clause has enabled an exchange of specifically low skilled labour often required for housekeeping and caring (http://www.migrationdrc.org). In recent context countries like Germany who is facing acute shortage of care givers have also added to reforms for better elderly care. This financial decision is crucial as they depend largely on migrant work force from Southern European countries (http://www.dw.com/en/germany-adopts-nursing-care-reforms-for-elderly/a-18047908). Although the reform is associated with statutory funding there is certainly concern related to rise of privatized companies of care with a reported and estimated rise of exploitation (http://www.dw.com/en/germanyadopts-nursing-care-reforms-for-elderly/a-18047908).

In this context the issue arises of whereas these global negotiations are taking place with all the countries standing with equal power or it is only opening to industrialist nations to extend their markets to poorest in urban centers (Gill,2004).

As the international migration has picked up speed and with that there is a need of understand the condition of this migrated workforce in the destined countries. The condition of irregular migrant workers is specially an issue of concern as reported by international convention. There are studies that focus on migrant workforce gives evidence of substandard food, labour abuse in Singapore and middle eastern countries (Bakan and Stasisulis, 1997)

The International Convention (United Nations, 2005) held on October, 2005 entails about the worse working and housing condition for the migrant workers. The convention tries to address issues of human rights and asks for state responsibility and that the diplomatic authorities of origin state should take care of their protection and security whenever cases of exploitation reported by migrant workers.

The migration of health professionals many a times is prescribed as the lucrative way for health professionals to receive better payment and life style. The percentage for global migration of health professionals stands at 6% for the doctors and 5% for the nurses (WHO, 2004). Apart from doctors and nurses there is a growing trend of migration of care givers.

The care gap that has taken place globally for the rising number of elderly has created the need for qualified direct long term care worker (Browne and Braun, 2008). Developed nations are turning to immigrant, Colour women from mostly developing part of the globe. The countries which have been traditionally focusing on family based care giving also have shifted its interest to easily available migrant care worker. Evidence for the same can be found in European countries such as Greece where the percentage of foreign residents stands at 7% of the total population and if unauthorised immigrants are accounted then it rises to 8.9% (Bettio, Simonazzi and Villa, 2006). The church also has played an important role in Italy in 1970-80s working as a recruitment chain between catholic female migrants and Italian families (Bettio, Simonazzi and Villa, 2006). These bourgeois families had primarily appointed this section of catholic educated lot of female migrants as maids. As

the time has progressed there is a shift and migrants from different countries (Poland, Ukraine, and Romania) have landed into the European nations getting involved in care giving of elderly. It is estimated that mostly those who seek such care services are no longer only bourgeois families. The demand for such household services is largely found in metropolitan cities in European countries as is indicated (Bettio, Simonazzi and Villa, 2006). As the number of female migrants involved in care work is considerably high, it is also important to understand who appoints these migrants and how their working and living condition is defined. Hoschild (2000) has coined a terminology to define this kind of movement from one country to another

calling it global care chain. This phenomenon indicates the transfer of women from lower income countries to high income countries to work as nannies, care givers. Further adding to this the care givers also face many challenges in terms of working conditions and wages. This analogy is important in the whole study of Health Care Aide both globally and in the context of India. The other major important aspect here is to know how formally these categories and their work is defined to understand the issues at work faced by these categories of workers.

Table 1 categories of Health Care Aide

3.1 The condition of Home Care as an Industry in Western Context

Nursing Aides:

These set of workers are referred, as per the available literature, in western countries as nursing aides who are working at nursing homes and are involved in dressing, feeding and keeping the patients clean (Foner, 1994).

Nursing Assistants:

The home based health care also has a set of care workers who provide long term care to patients in terms of fulfilling their clinical needs such as administering of drugs, checking of blood pressure, injection (Fuzy, 2003). This occupational category of nursing assistants is also certified in nature. There are training processes and training manuals created for this category. The job profiling and working conditions for this category is much clearly laid down in the training manuals as compared to home health aides.

Home health aides/ health care aides:

The nursing assistants often take care of such needs of patients at institutions, whereas, to take care of ADL activities after discharge from the hospital the home health aides are appointed (Stacey, 2006). This section of care workers are engaged in non-clinical activities such as personal care, cleansing, bathing, dressing, meal preparation (Stacey 2006). Home health aides are considered to be a group of workers who increase the efficiency of the skilled workforce, such as, nursing assistants responsible for clinical home based care. This section of workforce is expected to provide personal and intimate care which would help the patient to fulfil home care needs which he or she is unable to perform on own. Such work profile speaks to a great extent of patient's need of companionship apart from physical support (Annene, 2007)

Despite the fact there is much better understanding of the type of care aides and also the regulation mechanisms of health care industry there are struggles around wages, emotional burn out vehemently present in the context of emotional burnout and long hours of work.

3.2 Exploitation of the Care Workers

One of the important issues that have emerged with the evolution of the industry is the exploitation of the care workers. The care work and the labour involvement itself are largely segregated (Annexure 4). The earnings of care workers may vary due to the various kinds of skills they require, labour market and government regulation of this process (Misra and Buddig, 2008). Here doctors and nurses have a higher wage levels in care work industry as opposed to domestic care workers, specifically women (Misra and Buddig, 2008). As Stacey (2006) also gives evidence that the skilled nurses who provide post operative care are highly paid. As literature suggests, the category of unskilled home care workers is really underpaid (Schneider, 2003). It is discussed that the wages of home care workers in countries like USA varies based on region, employer and whether the employees are unionized (Stacey, 2006). However, out of these home care workers, the worst problem is faced by the selfemployed as they have no outside agency as an employer to bargain adequate wages for them (Schneider, 2003). Moreover, the whole health care industry is often criticised as a way of reducing public spending as the cost of care at institution has been transferred to unpaid care givers in family or low paid care-givers available through this emphasis on home based care (Aronson and Neysmith, 1996). The wage conditions are extremely worse owing to which the care workers often opt for multiple works, leaving them exhausted and still without adequate payment at the end of the day. It is stated that often a care worker does not even receive the minimum wages (Howes, 2006). Stacey (2011) in her study entails the extra burden of the Home Care Aides through case narratives:

"Mavis proved to be demanding and difficult woman to care for – insulting Lete for being overweight and accusing her of theft Lete wants to work full time caring for Mavis but such a change would require her to leave the night shift at ware house that pays six dollars an hour...... Between her two jobs Lete works nearly for 72 hours. She says that the hours are needed to

pay rent and send money to her family back in Mexico." Lete is a health Care aide (Stacey, 2011, p.25)

3.3 Burn out Issue, Perception on Low Wages and Long Hours of Work

The other aspect which is also forsaken is the psychological and social wellbeing of those who are part of this industry. The care-giving process to an ill and dying patient takes a massive toll on the care-givers. Literature suggests that spending time with such patient's causes psychological distress amongst care-givers (Ramirez et al 1998). It is indeed important to analyse how these low level health workers find dignity in their work. Foner (1994) has tried to capture the life of nursing aides in nursing homes stating that literature mostly talks about the care receivers and their family not bringing into picture the stress level, coping mechanism of these care worker living under control of strict bureaucratic setting (Foner, 1994). She has studied the ways the nursing aides made an effort to maintain autonomy and dignity in a strictly bureaucratic set up holding control over her labour (Foner, 1994). Though this primarily talks only about nursing aides in an institution, Stacey (2006) understands how the lowly skilled home care workers deal with stress, negotiate for autonomy and try to find dignity in their work. As discussed, home care aides apart from the problems of undervalued and low paid work also pointed out that overwork and added responsibilities create constraints (2006). Many of the home care aides mentioned creating a friendly bond with the patient and ending up working for extra hours (Stacey, 2006).

3.4 Extra Working Hours

The home care aides often tend to work longer than decided as bathing, cleansing demands excessive physical labour (Stacey, 2006). In many cases where such workers are self employed they undergo exploitation by working for extra hours for which no payment is made (Schnieder, 2003). Thus, the care aides often complain not only of emotional fatigue but also an exploitation of physical labour.

4. The Care Industry and its Growth in the Indian Context

The context of care work is also discussed in some of the literature focusing on issues such unpaid care work, care work being undervalued and the shift of care work from household to market. The inequality in terms of gender is evident in findings of one of the studies (Palriwala & Pillai, 2008) which focussed on understanding male and female labour participation in paid and unpaid work. The study categorised the work into productive (paid in nature) and non –productive (personal and unpaid in nature such as, taking care of child). The data collected both from rural and urban areas in Haryana had revealed that most of the male members were associated with productivity, whereas, majority of women were involved in work that is non productive in nature, primarily indicating acts of care giving (Palriwala and Pillai, 2008). Indeed, women often have to juggle between care giving and own work due to lack of affordable options, as it is only women who are considered responsible of caring in a family

However, although it is discussed that much of the care related work in household, such as raising of child, taking care of the sick, are performed by women, there is an argument that in urban India women have been involved in work outside house for earning livelihood, leaving a gap in care giving in family (Palri wala & Pillai 2008). Hence, in urban context in India there is a scope of care-giving growing as an industry. Web search was conducted to explore if the care work has found its place in market and agencies outside home are engaged in providing such care in urban Indian context.

As discussed above the growth of care work as an industry has become possible in western context keeping in view the care gap that had come because of family disruption. The market has also played a significant role in rendering care giving process, at home for palliative care and care during old age, the form of an industry. A section of literature discusses about the need of paying attention to palliative care in developing nations. It argues that there is serious need of creating palliative care and a specialist discipline and institution need to be built for such care, as developing nations account for 3 million deaths from HIV/AIDS and 6 million deaths from cancer (Lacey and Queen, 2007).

Literature also indicates presence of a geriatric population in India (Nath & Ingle, 2008). This section of population has a distinctive need of care, as old age is marked with chronic illnesses, which needs both emotional and clinical support. As argued, the ageing population in India also has seen a rise from 1991 to 2001 and would have a projected growth, reaching 320 million by 2050 (Nath & Ingle, 2008). As argued, there is a need of discussing the issue of care for this old age population at various levels. Some of the literature discusses in detail the models through which the old age care can be handled by institutions when the families are not taking care of them. It is discussed that geriatric care would need participation of state, civil society organisation and hospital settings (Chaubey & Aarti, 1999). This set of literature also speaks about a need of comprehensive care package which includes physical, psychiatric, social, family and economic, nutritional and rehabilitation aspects. In Indian context as argued, there is a need of strengthening geriatric care in hospitals, strengthening of hospice care movement, day care and rehabilitation centres (Chaubey & Aarti, 1999).

Institutionalisation of geriatric care and palliative care has also been broadly discussed in recent news in the context of India. Here, the need of care-giving at home is recognised as of high significance; however, it questions the ability of care givers within the family to cope with the care-giving process as it is highly demanding in nature. The need of a trained health care worker has been a huge demand from the families with terminally ill patients.

5. A Rising Industry in India

Women workforce in Indian scenario has been extensively associated with informal industry. Palriwala and Neetha (2010) has given a detailed understanding of the present network of informal and unorganized work. The GDP has grown to 6% annually in the period of 1991-2005. However even with that growth rate, there is a very minimal participation of women in the economic activity has been extremely on lower side with only 29% (Palriwala and Neetha, 2010).

The study reiterates the gender inequality that exists in Indian context specifically in relation to informal work both in rural and urban context with a

61% of women being a part of unpaid family work in the year 2004-05(Palriwala and Neetha, 2010)

As the extensive female participation in the context of unpaid or lowly paid care work is being discussed, it is noteworthy that a large portion of such workforce also works as domestic help mostly performing household chores.

The recent NSSO data showcases that the statistical figure for domestic worker has increased from 1.62 million in the year 1999-2000 to 2.52 million in the year 2005-2010 (Ganesh,2013). The aspect of feminization surely finds its presence in the context of domestic worker as 75% of increase in domestic workforce is surely accounted for women (Ganesh,2013).

Historically women have been performing household tasks. The shift of such work from being unpaid informal household based tasks to paid work has not however changed its key feature of being women oriented. The discussion of nature and extent of domestic workforce is very essential in the context of care economy as majority of work performed by these workers is centred on household chores, taking care of children and elderly.

In recent times the care economies which have stepped out of the realms of the households and have entered the markets involve self employed domestic workers especially in the context of developing nations (Mehrotra, 2010). The availability of labour force for enabling growth of such a care economy also has been possible due to rapid migration to urban centers. In Indian context a large number of women have entered into the cities and have been working as domestic workers (Mehrotra, 2010).

The major issue with the section of domestic workers whose working range is similar to that of trained care workers is that of immense difficulty in assessing their wage and working conditions and it is important to note that the there is a very limited legal provisions for such workforce in developing nations like India despite the rapid growth in migrated workforce (Mehrotra, 2010). This blurring boundaries or unplanned entry of no health care workforce in to health care work also can be attributed to dearth of adequate human resources in the context of India(Vajpai, 2014)

Based on the web search, it was evident that care workforce is particularly present in the urban context, specifically in metropolitan cities like Delhi that provide long term care to chronically ill and ailing old population for exchange of money. The search also revealed that the key players are hospitals, the profit and non-profit agencies and the self employed care workers. Private hospitals, like Max Life Insurance provide home health care nurses who are skilled and provide home based services on call (www.maxhealthacare.in). It also provides health care-giver who provides services to household pertaining to bathing and dressing and also retains a timetable of activities that are good for the patient.

Apart from hospitals there are also non-profit and profit agencies which provide care workers. The kind of care provided is mostly related to long term care to terminally ill, old-age care, care provided to patients suffering from physical disability. The non-profit agencies are catering to creation of such workforce for helping a patient in bathing, taking medicines on time. organizations such as St Stephens in Delhi have been training women with very low educational status with basic understanding of diseases and home health care for serving as low skilled health care worker. Secondly, there are also organisations which have been rendering "hospice care" which is palliative care or continuing care for terminal patients of cancer (http://cancersupport.aarogya.com/shanti-avedana-sadan/blog), care for the elderly (www.eldershelp.org) patients of critical mental illness (www.alz.org). Apart from this, there are bureaus that provide home nurses and low-skilled home health care worker (http://www.sshomenursing.com). There is also a section of self-employed women working as health care aides without mediation from any agency. In Indian context, to explore into the dimensions of care work it becomes essential to understand the nuances of domestic work as they play a great role in care work as well. The growth in the numbers of domestic worker is surely influenced by the change in economic structure which is from agrarian based economy to service based economy (Palriwala and Neetha, 2010). There is a huge influx of population migrated from villages after a decline of agricultural economy.

Although there is an industry growing in India in terms of home health care there is a paucity of literature for the same. Apart from this there is also a blurring of boundaries between a domestic worker and home based care aide in India. In Indian context, those who are domestic helps are also providing care to ailing and dying patients. As argued in official documents, a domestic worker's responsibility in India covers not only domestic chores such as cooking, cleaning but also many other works such as driving, caring for old, sick and children in the family (www.ncw.nic.in). The major concern here is that there are no defined duties for any domestic worker and there is dearth of regulation from the state.

As far as regulation is concerned in Indian context, hospitals, such as Max, have set some standards for home care aides by entailing their specific duties (www.maxhealth.in). Even institutions, such as St Stephens, are running their program of provisioning home care aides governed by the Clauses of Minimum Wages Act while fixing wages and working condition. As far as state intervention is concerned, the National Trust under the Union Ministry of Social Justice and Empowerment started Sahayogi, a program which created a pool of trained care givers for persons with disabilities (Bhatnagar, 2013). However, these are only a few organisations imposing regulations on the growing industry. The industry is still in its nascent stage and there are still issues concerning wage of these workers. Indeed, care-givers complain about the absence of adequate labour law governing wage conditions and absence of a lobby for creating better working conditions for the home care workers in India (Perappadan, 2013). There are several placement cells and self employed domestic level workers are not impacted by any regulations. Although there are movements that have started in the country to protect the rights of domestic workers there are very few legal procedures for the same. As long term care for patients in households often gets blurred with duties of domestic help, it again becomes a concern while understanding the exploitation of home care aides in India.

Additionally in the context of India the health sector reforms (Tyagi, 2000) led to many changes in health care economy. The advent of liberalisation and privatisation seemingly is also present in home health care industry in India

owing to presence of big health care brands like Max Hospital. There is surely a need to scrutinise the impact of privatisation on home health care.

To conclude as there is very less concrete data related to growth of care giving as an industry in India, but existence literature showing its presence, there is a need of looking at the industry thoroughly with an engagement of agencies that provides such care. For this purpose mapping of industry is crucial and also it is important to draft a methodology to reach out to this industry that has begun its growth in India. The present study here will asses based on information of western countries as frame of reference and the information obtained related to paid and unpaid care work in India's context.

Chapter 2

Methodology

This chapter will entail the methodology adopted to design the study. This will include broad objectives and specific objectives, sampling technique, inclusion and exclusion criteria adopted for the study.

1. Conceptual Framework

Based on the understanding derived from the concepts and the issue of transition of care-giving from a household affair to a commercial concept in western context it will look at the situations in urban centers of India. There is an expansion of the market in cities in India boosted by the demands and availability of a workforce. The public, private players and also many international companies have been playing a role in setting up and sustaining care giving as a commercial concept. Hence it has become important to understand the extent of care-giving industry specifically in urban India where it has become a purchasable product. As India has stepped into urbanization with expansion of metro cities, the structure of family has changed. The family members no longer necessarily live together in a common place. The geographical distance has created a care gap for family members. Care-giving has also come out of the realm of home in such cities in India where a section of population has been demanding care- givers from outside the family, owing to their engagement at work place. The priorities of women also have changed to concentrate exclusively on earning wages outside home in such urban centres. The affordability to bring care-givers from outside home has also increased. This demand is accompanied by a supply of the care workers who are provided by various sources which are mostly commercial in nature (private hospital, NGOs, national and international for profit companies). Although there is an emergence of the Care industry, it is still in nascent stage in Indian context. In western countries where the industry has already grown extensively, there has been discussion on wage conditions, the social and economic background of this workforce and also their issues. However in the context of India, as it is in a nascent stage there is very less discussion on

issues related to working and wage conditions of the workforce, the mode of operation, the financial worth, quality control, regulations, stakeholders associated with the industry. In its commercial sense, a market is building up in India but there is very less discussion on socio- economic background, wage conditions, emotional burn out issues specific to this workforce.

The present study aims at exploring the dimensions of this industry in India. Firstly, it is going to explore how this industry has come into being in Indian urban centres. It also would explore who are the stakeholders reinforcing this industry both in the context of demand and supply. Thirdly, as is evident in the western context, there is a genderization of workforce. The study will explore the gender roles in this industry in the Indian context. As there is no regularization, the study would explore how this industry is functioning in terms of wage and working conditions and training of the workforce. The significant aspect in Indian context is also the large presence of workforce that is self-employed care-givers and at times functioning as health care aide alongside working as domestic maids and in other occupations. Moreover, it is important to understand the social and economic background of this workforce keeping in view that the industry involves cleansing of others, which in Indian social context are considered to be tasks historically performed by lower castes.

2. Research Questions

- What is the nature and extent of care industry in Urban India?
- What are the issues reported by this workforce in terms of working condition, wages, burnout?
- What are the differences in the working conditions of those who are employed through an agency and those who are self-employed?
- Is there any gender variation within this workforce?
- Which socio-economic background these section of workforce belong?
- What are the mechanisms of regulation of such workforce for NGOs, private agencies and for hospitals?

3. Broad Objective

To explore growth of care- giving as an industry in terms of its structure, stakeholders, demand and supply, the nature of such work, the type of workforce and issues associated with this workforce in urban context in India.

3.1Specific objectives

- To map the agencies involved in providing home care workers in Delhi
- To understand the system of functioning of these agencies as far as engaging with both demand and supply side of care giving.
- To understand the processes of training, recruitment and marketing of the care industry.
- To understand the range of stakeholders associated with care as an industry.
- To understand about the type of workforce, their socio economic background and gender
- To explore the issues of the workforce in terms of working conditions, wages and burn out

4. Study Design

The design of the study was exploratory in nature as it would serve the objectives of exploring into the nature and extent of home based care giving in urban India. Although it has been over a decade since the industry has began there is not much research conducted in the area. The present study looked in to the type of the industry that has grown around care work. It intended to gather information about how and why care work had moved out of the realm of households and what had been the nature of such work as well as the workforce involved in the same.

5. The Sampling Technique

The study aimed to undertake Delhi as a case study. The primary reasons for taking Delhi is that it is one of the largest growing metro centres in India and also as is depicted through web search has a very high number of placement cells and institutions working for creating cadre of health care aides. There is

an involvement of NGOs and also private hospitals in Delhi in building this industry. There is also an institution for training of health care aide in Delhi, which will provide the scope of learning the state role in provisioning and monitoring of care services. Moreover it has varying segments of population that can serve both demand and supply side of care industry.

The study did not choose specific areas of Delhi. The primary idea was to capture the care aides and the nature of the institution they were working for, hence the sampling technique adopted was to identify various kinds of institutions providing care and then interviewing the care aides appointed by them. The study also aimed at interviewing the care aides specifically trained by the government body National Institute of Social Defense for the purpose of care giving. The second category of care aides was self employed and for them snow ball sampling was used and help of existing network of care aides was taken to locate this category.

The key informants such as the trainers, employers and family members (who have opted for paid caregiver) were also be included to understand their approach to the industry and interaction with home care aides. Few of the informal care aides were also included in the study to understand the aspect of family care giving in India, the issues faced by them as opposed to paid care aides. The idea was also to understand the reason behind not opting for paid care aides and if any perception related to the industry can be derived from the same. The study followed an inclusion and exclusion criteria to derive at the sampling technique. The criteria was adopted to ensure that the industry of care giving, the experiences of care aides functioning is captured well.

a) Inclusion Criteria

The study includes Health care aides who are trained and are working with patients. As the preliminary visit to St. Stephens have shown that it is difficult to find a Health care aide who are providing one type of care (elderly care, care to terminally ill, care for mentally ill, short term care) it includes care aides involved in different kinds of care giving processes. However study included a large number of care aides who had been associated with palliative

care giving once in their life time. The types of care giving were not at the core as the study primarily aimed at understanding the health care aides.

The study also included care workers who have not received any training but also are providing care to elderly, dying patients and mentally ill.

It included families with informal care givers (care givers from the family) to have an comparative understanding of what is the reason for certain families to opt for paid care givers whereas a section of population within the same class living in urban centers engages as informal care givers. In this case the study also included families that have once opted for paid care givers but had changed to informal care giving in course of time.

The study selected a co-operative society in St Stephens (an NGO) to understand the role of civil society organisation in care giving, Max Hospital to understand the functioning of private stakeholders (Max Hospital found through web search), care aides working in placement cells located in Delhi (found though the network of care aides during data collection process) and also self employed care workers across East, West and South Delhi.

b) Exclusion Criteria

The study excluded nursing assistants and domestic workers who are not involved in providing any home based care to terminally ill or elderly.

Table 2: Sample size of Health Care Aides and Family Care Giver

Agencies	Type of care work	Number	of
		respondents	in
		each category	
Government	Care for palliative care and palliative care	7	
institute	with elderly		
Private Hospital	Care aide for terminal illness, surgery, and	6	
	elderly		
Hospital	Care for children	3	
St Stephen	Care in all categories(elderly care, terminal	6	
placement cells	illness as the experiences are not exclusive)	6	
self employed		6	
Can Support		2	
Family care		5	
givers			
Total		41	

Table 3: Sample Size of Key Informant

Key Informant

Key informant	The concerned category	Number of	
		key	
		informants	
The member of the family	Self employed health care		
who have kept a self	aide	3	
employed health care aide			
The owner of the placement	The health care aides		
agency	appointed by placement	3	
	agency		
Co-ordinator of Training	Those who train in the	3	
body	training institute	3	
The manager at private	Trained health care aides at	3	
hospital	private hospitals in Delhi	3	
The trainer at Government	The trained health care aides	3	
training body		3	
Total		20	

The sample was also grouped in to male and female categories to understand the male and female participation in the industry and if it is genderised in nature. The sampling have included more key informants from families to gain extensive understanding of the primary reasons for Indian urban families to opt for care giving.

6. Data collection Process

The present study is qualitative in nature. In-depth interviews were conducted with health care aides to build an extensive understanding of the concerned issues.

Secondly, interviews were conducted with key informants for understanding their role and perception in Care industry and development of care economy.

a) The Interview Guide and Schedule

The data was collected with interview guide for the health care aides. The guide captured the detailed version of the care aides (Annexure 5). Firstly the interviews primarily focussed on the process in which the health care aides had entered into the services. This included reason for entering into care services, the sources of information they followed to gain knowledge about such kind of work. The second aspect was to trace the type of care work the care aides had conducted in the process of care giving and the varying experiences while transitioning from one type of care to another. The experiences of care aides with families are also important to understand to know how they had been able to cope with the role of care provider for someone outside family. The idea behind this theme is to explore the relationship between care aides and family members. There is also a need to understand the relations of the care aides with employees, the negotiation skills adopted and hence the interviews also included the experiences of care aides in terms of wages, welfare issues, leaves, discussion on challenges of care work with the agencies. The health care aides experiences emotional and physical burnout as also covered in the interview schedule. This also included if the care aides had faced any experiences of sexual violence in the process of providing care. The perspectives of care aides about care work was also included in terms of its worth as a growing industry, scope of growth for themselves, and the assumption of it being a work derogatory in nature. The care aides were also asked if the whole industry of care giving has remained only exploitative in nature or have provided better livelihood opportunities for them as well as fulfilling the care need.

The study explored the profiles of health care aides in terms of socio economic background including age, caste, class, gender and migrant status of the health care aides, wages, and other employment benefits through a set of close ended interview schedule

An interview guide for family care givers (Annexure 6) was also generated to understand the role of family members in care giving. This would also explore the role of female members within families for the same.

b)Key Informant Interview

The key informant interview (Annexure 7) aimed at understanding the perspective of the person who is part of the employing system. The major themes covered were the reason for being in the industry, the demands for such home health care, how the supply chain is managed, the working condition, regulation of the whole industry, and the socio economic background of those who seek such employment.

c) Observation as a Tool

The study included intensive field observation accompanying the home care aide in their worksite. This included observing the training processes of the home care aides to understand the orientation of this workforce. The observation included primarily the following aspects: The observation will take places based on the themes of the nature of interaction between the health care aides and the client, the nature of interaction between family of the client and health care aides, the nature of interaction between employing agency and health care aides, the care giving responsibilities performed by the health care aides.

d)Web Search as a Tool

Web search is one of the methods adopted in the study as a tool. As there is a huge presence of information on websites the study also has used website data to create maps of services across Delhi about various kinds of care services. The data is analyzed based on website data and are presented in the forms of images and excerpts from the websites to understand the pattern of growth in care industry, the stakeholders, investors and also the placement of care aides. For this purpose data has been derived from web based job portels, web journals and reports of business magazines, documents and evidences created by universities on growing marketisation of care work and also websites of various organizations, firms that have been developing post hospital care as a paid service.

Table 4: Operational Definitions

Home Based Care:

This concept implies in the study care which is provided at home to terminally ill patients and those who are old in age. This kind of care includes activities which otherwise an able bodied person is capable to carry out.

Health Care Aides:

In this study the terminology "home care aides" implies those who are getting paid for providing palliative care and geriatric care, which is unskilled labour in nature.

Self Employed Health Care Aides

The home care aides who are working as domestic maids and are employed by self are companies for terminally ill and also provide home based health care.

Placement Agencies

The placement agencies are those that work as a network, which provides domestic aides to the households for carrying out their household chores and also for providing a helping hand for activities of daily living (ADL) to elderly, terminally ill patients.

Activities of Daily Living

The above concept would be utilised in the study in the context of activities which are necessity of daily life. Bathing, eating food, using toilet and walking would fall under category of ADL.

Non-governmental Organisation

In the context of this study the non-governmental organisation would imply places which are running training institutes for home care aides.

Private Hospitals Providing Sources

The private hospitals here would be those who are providing skill training as well as are providing such trained workforce to families who are looking for home care aides at homes.

Palliative Care

Palliative care in this study is considered the kind of care which is provided to terminally ill patients. In this study the palliative care would refer to care provided to terminally ill patients at home.

Informal care giver

The informal care givers are those who are members of the family and are providing care to child, elderly or terminally ill.

Other Care Work

As it is difficult to identify specialisation only in palliative care giving the study will have to include the care givers who have been providing range of care services such as geriatric care, care for mentally ill, care for children along with palliative care. These care work would be defined other care work in the study.

7. The Phases of Data Collection

Pre Pilot Study

Apart from this, preliminary visit to St Stephens, one of the NGOs that have developed such a model for training home care aide in Delhi, was visited. This visit included an understanding of possibility of data collection pertaining to health care aides; a preliminary level of understanding about the kind of functioning the health care aide program carries. The NGO is providing training to women from the community on basic skills such as taking care of elderly and terminally ill. The program is running through a self help group.

The limitation in the pre-pilot study was the challenges faced in understanding the hospice care centers. Few of the hospice care centers denied permission for the study. However in the second phase of data collection one of the hospice care centers run by Can Kids was visited to understand the processes adopted in palliative care giving and the role of care aides in such institutions. This was necessary as these care aides although would not stay at home but do home visits and are constantly in touch with the families. Thus this could give a comparative understanding with home health care.

8. The Second Phase of Data Collection

The second phase of data collection was to seek permission from the identified agencies which are a non-governmental organisation, placement agency, government organisation, private hospitals training home care aides. The researcher framed application and provided synopsis to Max Hospital, St Stephens, and NISD for clearance.

The researcher came down to selecting Max Hospital and NISD based on web search. Apart from Max Hospital few other hospitals like Apollo was also approached but they refused access to information. The first and foremost task here was to design the tools and meet the chief functionaries of the care giving department. The researcher went to home health care department of Max and met the director of that entire program. Initially challenges were encountered as the hospital refused to provide any information until and unless one works at the hospital as an intern. Later permission was granted with support from the Director and the process of permission began with submission of the synopsis and the tools. The unit at Max has a supervisor who looks after both institutional and home based care at the level of hospital but the business is primarily handed out to a company called Shine and Standards that looks after both home based care and housekeeping. After going through the interview schedules the manager of Shine and Standards at Max Hospital granted permission.

The second phase of data collection at Max hospital began with segregating care aides from the profiles they had provided both on the basis of availability and their experiences. The researcher tried to include care aides both having long and short years of experiences in care giving. Equal male and female ratio in sample selection was difficult to achieve as there were not many male care attendants and hence the number of male care aides interviewed were very less in the context of Max Hospitals. In the beginning of interview consent forms were signed by the respondents.

The second institute covered in the data collection phase was St Stephens Society. As the researcher already had entry into the institute during pre pilot phase taking permission was not very difficult. The selection of care aides was done based on inclusion criteria. However here as well finding male care attendants was difficult as there was no male care attendant. The researcher got a profile of the care aides working in past two years and included those with short and long years of experiences in care. In case of St Stephens most of the care aides also had been in institutional care with St Stephens's hospital for bed side assistance.

The third institute included was the placement cells. Two of the private cells were selected for this purpose based on information from families of patients. The placement cells identified provided home health aides and the same method of selecting sample from a profile provided to the researcher was adopted. In the case of placement cells however the researcher discussed with the owner of the agency to segregate between the sections who have only worked health care aides and not as domestic maids. It included care aides who initially worked as domestic maid for some time. The placement cells were also showed the tools to be used and consent forms were signed with the respondents. The interviews were conducted both at the workplace and at the homes of the families where the care aides were working.

The fourth category of institute included was that of the training institute NISD. After completing the process of permission the center provided a list of students who have passed out and are engaged with different institutes. The respondents were contacted over telephone after getting a short overview about them from the trainer and was shortlisted based on their availability. The interviews were conducted both at the workplace which is home of the families they were working for or the office that employs them. In this case many of the care aides who were involved in institutional care or have never been engaged in care work despite the training were avoided. The care aides who however had left care work in between and then again joined were included.

The fifth category of care aides were that of self employed. As snow ball technique was adopted the self employed care aides were selected primarily based on the criteria that they were involve in care work and secondly that

they were available. This included both former domestic maids and the self employed nurses who worked as care aides.

Apart from this the informal care aides were interviewed. They were also identified based on snow ball sampling. The key informants such as family members who opted for paid care work were also interviewed. In the second phase the doctors from St Stepehns society, the trainers at NISD, the managers and supervisors at Max Hopsital and the owners at placement agencies were interviewed. Apart from this the researcher also visited the care home of Can Kids who provides palliative care for cancer patients and interviewed care aides and the clinical nurse.

9. Data Analysis plan

The data analysis plan included collating data collected from home care aides working for different employment sources. As data collected is descriptive in nature, method of analysis for qualitative data was adopted.

The data was transcribed and then a thematic analysis was created. Emergent themes were identified and the quotes shared by the respondents were divided under themes for the purpose of writing report.

The quantitative data was analysed through creating a list of variables and then entering it into a database. These variables included information on age, social-economic status, migrant status, daily schedule of the care aides and also their wage profile.

10. Ethical Consideration

The researcher took into consideration following aspects as far as ethical issues are concerned. The study also had gone through a process of ethical clearance at IERB (International Ethical Review Board) in JNU presenting a set of consent forms and institutional permission formats before entering in to the phase of data collection (consent forms attached as Annexure, 8, 9,10)

Integrity of data:

The researcher took into account the fact that the sources secondary data which has been referred in the study needs to be acknowledged. Secondly the researcher had taken necessary permission from the institutions before collection of data.

Consent of the respondents:

The researcher ensured that the respondents have provided their consent for answering the questions put forth to them. The researcher ensured that she does not probe the respondents for any question which she or he is not willing to answer.

Maintaining sensitivity:

Keeping in view the fact that care giving to terminally ill patients can imply stress and emotional burn out, the researcher maintained sensitivity towards the issue and avoid posing questions that can create utter discomfort amongst care aide.

Confidentiality:

The researcher would maintain confidentiality in terms of identity of the respondent. The researcher restrained from publishing any data which the respondent are not comfortable of presenting.

Explain objectives of the interview to the respondent:

The research involved questions related to their wage condition and also behaviour of employees. The researcher ensured that the objective of conducting the research to explore in the aspect of their wage conditions was explained to the respondents. It was clarified that there would be no immediate effect in terms of increase or decrease in wage, on their job after the study

The following section of the methodology will deal with the profiling of the respondents and the area covered during the process of interviews.

11. Profile of the Area for Case Study

The study had selected Delhi as a case study. The primary focus was on care aides and as they had worked in multiple locations it was difficult to select one particular zone. The respondents interviewed primarily were in South, East and West zones of Delhi. The care aides were working in Lajpat Nagar, Sundar Nagar, Ashram, Vasantkunj, Pachim Bihar, Gazipur and also in NCR regions of Delhi (Gurgaon).

12. Terminologies Used

There is no definite terminology used for the position of care giver and it has found different nomenclature in different care networks. It is often noted that the word home care has been loosely used to define the work profile but the concept is not comprehended as exclusive and is confused with institutional care or nursing. The terminologies used across various care giving network is given below.

Table no 5: Terminologies

Category	Terminology	
St Stephens (NGO and	Bua (generally for child care), Care Taker	
hospital)		
Max Hospital (Private	Home Care worker, Home Nursing aid	
Hospital)		
Placement cell	Care assistant, Care worker, care giver, Nurse	
	assistant(no definite terminology)	
Self employed	Care taker, care giver, home care assistant	
National Institute of Social	Care assistant, bed side care givers	
Defense		

In case of informal sector as in care giver in family is concerned all of the respondents were female. Most importantly in this aspect the women are the one who is taking care of both male and female patients irrespective of their own gender. The care givers interviewed are daughters, in law, daughter in law and wife. Few of the female care givers however reported getting assistance from the male members of the family.

Table No 6: Key Informant Profile

Name of institutes	Type of institutes	Number of key
		informant(s)
National Institute of	Training Institute of	3
Social Defense	Ministry of Social	
	Justice	
St Stephens Society	A co-operative society/	3
	Training Institute	
Help Age India (An NGO and	3
AIIMS)	government hospital	
	institute	
Max Hospital (Shine	An contracted out	3
and Standard)	company of Max	
	hospital	
Placement cell	A profit company that	3
	employs nursing aides	
	and care givers	
Family member of	Self employed category	3
self appointed health		
care aides		

Chapter 3

Home Care Industry, Genesis, Stakeholders, Emerging Concepts, Market

This chapter looks into the structure and nature of care industry in Indian context based on web analysis and also primary data. The webs analysis has primarily focused on how care industry has taken a shape in the context of metropolitan cities of India. The sources that will be referred here are websites of institutes, newsletters, blogs, news reports, business journals, selling and marketing websites, and online information portals of general services. This will look into evolution of care work from unpaid to paid in Delhi based on data interviews .The second section will look into the typologies that have evolved and how they contributed in delivering of home health care. There will be an exploration into what services it entails and how these services are delivered. The chapter also looks at the aspect of privatisation, analysing the stake of private companies in the industry. This will also look at stake of not for profit organisations, presence of state regulation and participation in the care industry both based on secondary and primary data. The chapter also explores the nature of self employed health care aide and their nature of functioning. Finally the chapter looks at family health care aides and their account of reasons for not opting for paid care giving.

1. Historical Evolution of Care Work

The questions that rise are how and when the need of bringing someone from outside for care is introduced in Indian context and who has been the primary stakeholders involved in the same. The care industry in Indian context is very nascent. The transition from family set up to hiring someone outside home is a phenomenon which has taken place only in recent past. The literature review in previous chapter also takes a look at this transition. The study based on its discussion with family care givers and key informants have also assessed this transition. It is evident that until recently the major cities caring posed more as a duty than work. Thus involvement of family members was an obvious part of the paradigm. Indeed the transition from caring being a duty to work has

happened due to many changes in family structures, the economics of family and also the changing nature of female roles within households. However there is also evidence available that this transition has not occurred simply because of the changing nature of families, but also families interest in pursuing trained support in few cases. This nature of transition shall be discussed in one of the sections in the chapter. Prior to that there is a need of discussing the premises on which care has remained within the household. In fact many of the reasons as to why care work has often remained within the household also become issues when a care giver is hired as the families often find to let go off that mindset that has been historically set As indicated by many of the informal care aides, they have been involved in such work for a long time in various settings. As one explores deeper in to the arena of care giving in families it becomes evident that it is a combined responsibility of other members of the family.

"I think the responsibility of caring falls on everyone in the house, although it is mostly my job to take care of mother in law of my daughter, all of us also share responsibility on days. Some days when I am not well or I have some work I am replaced by my son. I think if someone is not well in the house, automatically everyone around starts contributing what they can. They indeed would do more if they would not have jobs or other work to do. It is a family responsibility for sure to take care of sick and elderly and it is there in our values and life style."-Roma, Family Care Giver, daughter of a patient, VasantKunj

Care system in the mindset of many has been considered as rather a task of the family and not to be handed over to any one external, thus there is also a tendency of handing it over possibly to someone in the family circle or extended family circle. Most of the families who opt for care giving also have opted for paid care givers. However it has been very difficult transition as the families had to undergo a change of view over letting someone encroach privacy and enter into the family system. This actually have posed problems for the care workers as well as the nature of care work being labour of love it is utterly difficult to project professional behaviour. Nevertheless one of the

prevailing opinion of a mass category of population over care work has been that it is better provided by family members as the issue of trust, love and more sincerity is higher when it is provisioned in that manner.

"The aspect of family being responsible as a unit was reiterated by many other informal care givers interviewed. It indeed has been historically so that the families, sons and wives would take care of elderly and there was no need of any external help. Time has changed now, me and my wife are very much part of this caring system and I personally would want to attend my parent. But I am not able to do so because of my job and neither my wife is able to work, thus we have my mother in law here. We opted for external support in between but it never has helped us as we could not always build that trust and expect sincere behaviour from the workers"-Nitin, Gazhipur, East Delhi, Family Care Giver

The importance of family members had been put in the pedestal for care giving and hence this also leads to the question of how and why there has been a shift in the thinking process of specifically urban classes, both major and smaller cities which now are promoting care work. This needs to be reviewed to understand the transition of care from home affair to paid one despite the preference for family care givers. As noted in the verbatim in the section above one of the reasons of the transition is for sure the change in nature of social and economic structure of families. The nature of the families is changing from joint or supportive extended families to simply unitary bodies thus leaving a vacuum for care. It is indeed followed by the obstacle of changing nature of work which is that the working style demands most of the family members to be out of house for more productivity and better economic gain. This gap is corroborated by another issue which is absence of women as primary care givers. Whereas the entire family is supposedly responsible for caring it is mostly considered a feminine job hence handled primarily by women with or without assistance of other family

"As I am a woman I feel my responsibility for care giving is more than anyone else, is historically. I believe that because I have done it for all my children and my husband and also other members of my family. Right now I am taking care of my mother in law as I am supposed to take responsibility for my family. I also stopped working because I was supposed to take care of my family. Although I thought of that many times but I could never work again. My mother in law is ailing and she needs support and my husband and I are not also comfortable hiring a paid care worker as she would not be able to do a good job for the family. Although I respect this decision but it makes life difficult for me as a home maker. My husband thought keeping a care aide is a new thing and he did not know and believed she or he would be able to do it as diligently as I was doing it. I felt helpless in many occasions, as my mother in law who is paralysed for last couple of years would probably need expert help. I also felt disconnected at times, as it is not so that I was taking care of my own mother. I had been taking care of her for almost over a year and now she is indeed more incapable and getting old also making her forget things. It is indeed a 24 hour job and I think it is not possible without any external help." - Ruchi, Family Care Giver, Vasant Kunj, Delhi

The idea of care giving has been crucial specially by women of the household, and it comes as duty to them and it often becomes burdensome either with work or other responsibilities. Richa who takes care of her mother suffering from dementia for years now, however it became very difficult to do so without external assistance in last few months when there is more pressure as her mother's health deteriorates with more and more inability to do daily tasks.

The second derivation is also that most of the informal care giver apart from finding it troublesome to manage both home and jobs also find issues related to lack of training for such care giving. One of the care attendants shared how she looked for information while taking care of her mother suffering from dementia. Indeed she shared; it is definitely a common problem as often the care givers would want expert support which is not available. She shared that although many suggested the option of keeping her mother at a dementia care centre, she wanted to take care of her at home. Henceforth she shared how it is important to have external trained support for care giving as it is a tedious and 24 hours job.

As per a majority of the people who are involved in care giving believe that change could be seen toward end of 1990s with a gap rising in care giving. As shared by the governmental organization a policy was drafted in the year 1995 as there was a need felt of care for elderly. A need was felt for training human resources as there was a rising care gap in the society specifically in urban centres of the country.

"Health care for elderly has always been a concern for the government. Therefore as a part of provisioning of health care for elderly under NPOP (National Program for older Person) many programs were designed. The government had decided to take care of economic and social well being of elderly. The issue of lack of care giving was being recognized and hence the unit of geriatric care started to train care givers."- Dr. Anindita, Trainer (National Institute of Social Defence)

The institution was built as a part of planning to meet the needs of the elderly under the aegis of Ministry of Social Justice. The major focus of the National Plan for Older Persons speaks for the betterment of elderly. The policy was designed in the year 1999 and it deliberated on promoting healthy life for elderly. It extensively talks about older person's need of shelter, institutional care. It further dictates the need of welfare at home and hence sharing responsibilities of care for chronically ill elderly by family members and society."

However one of the owners of placement agencies has stated that the need for external care rose around 1990s and it had risen to a great extent in last decade.

"If you ask me when people started needing care provisioning, I would probably say that they always needed it. However as per my experience the need has increased now. We used to provide nurses for assistance since 1990. Now I get enough demands and specifically for bed side care assistance. This is important for families with parents living all by themselves. We used to hire mostly nurses only earlier who would work for bed side assistance, but now we have specific category of home care aides for this job as well"- Mr. Verghese, Placement cell

Keeping in mind that the need was felt and there is a vehement present of a network, it is necessary to understand about the kind of stakeholders involved in the industry. This section will look into the role of public and private entities that have facilitated the transition of care work from unpaid to paid mode.

2. Emergence of New Categories

There is a whole range of stakeholders who have contributed in creating a market around care gap. There is a need to understand how these care networks negotiate both with care receivers and care providers. They have different kinds of objectives and modalities of functioning. These bodies are very distinct from each other and thus the following section would delve into functioning of each institution and how they had been managing the network of care aides. This also looks into how they have been training the care aides and integrating this workforce in to the whole system of health care provisioning.

In last one decade there is a growth of markets around care giving as an industry. The caring business has been progressing ever since making it lucrative for its developers and creating employment. The industry is called home health care industry as per business terminology. The business world estimates analyses that the industry which began around 2000 in unorganised and scattered manner now has caught attention of many investor and entrepreneurs. As home health industry as shared in one of the websites the care work has grown as a business and more and more in Indian context in recent decade (approximately since year 2000). It is noteworthy that the home health care industry is dependent on many factors and is associated with many

other organisations. As derived from both primary and secondary data the care giving agencies have evolved at different phase and also have defined its health care aides with different terminologies.

There is a need of understanding the kind of home health care services provided by these agencies and the nature of such services (Annexure 11) The significant aspect is that all these companies have used their own terminologies to define the health care aides. There is certainly a similarity in the usage of these terms, but they are not the same. Most of the companies can be divided in to private for profit and not for profit agencies, training institutes, placement cells and self employed health care aides. The work profile for the terminologies used for each category has certain similarities in terms of the nature of their work which is to take care of mostly activities of daily living. Apart from that there is an addition of range of activities in all the categories of the health care aide workforce.

The other issue significant here are that these agencies also have differential status in terms of their nature. They are running as training institutes under the aegis of Ministry of Social Justice like National Institute of Social Defense as well as societies registered under societies registration act(1861). Many of them are companies registered as for profit entities as well. Max Home Health Care, Apolllo Home Health Care, the online service portal fall under this category. The placement cells are often swinging between working as registered private companies and completely unregistered one. The placement cell bill is still under review, hence creating loopholes in regulatory systems for this category

2.1 Online Service Portal

These companies are based on online marketing system. They sell a range of services related to home care on their websites. There are approximately 20 such companies found through web search.

"Why wait to see a doctor, when there's a doctor waiting to see you? The next time you or a loved one needs to consult with a doctor, have the doctor

visit you. At home, at your convenience."http://www.pramaticare.com/services/assistive-care

As indicated in the sentence above from one of the websites of home care giving agency it goes far to the extent of covering all possible services required during post institutional phase. The market and the entrepreneurs want to ensure more and more business with a promise of delivering a range of facilities. The definition of home care is much more comprehensive as per the profit oriented care networks. The home care giving the present study is catering to is called home health care service by these companies and this includes bed side assistance and help for activities or assistive care service as is called by many of these companies of daily living for patients post operation (post surgery care), elderly and patients with terminal illness for end of life care. The health care aides are called Home care attendants, Patient attendant, General Duty Assistant, Assistive care attendants.

Table No :7 Care Services in Online Service Portal

Assistive Care Service (ACS) is a Medicaid-based, state plan that provides care to eligible recipients who require an integrated set of services on a 24-hour-per-day basis.

ACS recipients must demonstrate functional deterioration that makes it medically necessary for them to live in a supportive setting and receive integrated services, whether scheduled or unscheduled. ACS includes:

Assistance with activities of daily living (ADLs) such as bathing, walking, toileting, etc.

Assistance with instrumental activities of daily living such as shopping or making a telephone call.

Medication administration and assistance with self-administered medications and

Health support observing the recipient's state of health and well-being on a daily basis and reporting changes to the health care provider as appropriate)

Day to Care: Personal Care

Maintaining Body Hygiene/ Bathing

Changing Bed and Bedsheets

Avoiding Skin and bed Sores

Ensuring Oral Hygiene

Urine Incontinence

Bowel Incontinence skills,

Incontinence and Toileting

Assisting in toileting

Controlling stains and odour

Emptying the drainage bag

Practical demonstration of exercises –Arm/hand; Neck;

Leg/ankle; Trunk (in bed); Legs (in bed); Arms and legs (sitting); Resistance; Sitting balance

Assistance in activities of daily living

Caring for someone in bed:

Adjusting the position of Patient

Ensuring the correct body mechanics while lifting

Efficient movement from bed to chair

Assistive Devices:

Prepare a List

Demonstrate the skills and use of the equipments -

- (i) Walker (ii) Crutches (iii) Others (iv) Patient lift and bathroom equipment
- (v) Walking aids, Guarding Walk

Preventing falls and straining of the back

Assisting in wearing footwear

Day to Day Care: Food and Nutrition

Knowledge -Nutrition and Hydration. The ways and means to provide healthy food is very critical and we ensure the same.

Skills:

Helping to eat

Managing timely medication

Day to Day Care: Ailments and Medication

Fever, nausea and vomiting

Pain, fatigue, restlessness

Anxiety, delirium, depression

Emotional challenges: Mental health and counselling, handling difficult

behavior

Fatigue, restlessness, anxiety, delirium

Depression, social and spiritual distress

Dementia, emotional withdrawal

End of Life, final Days, when death occurs

The companies (Annexure 12) have made it a systematic process where a customer can browse, read and chose. There is a process of registration with a depiction of services offered. One can also mail for a quote and the company sends personal mail to the person seeking information. These business ventures offer personalized services, individualized plans for the customers with also a method of feedback and constant monitoring. One of the business propositions of these companies are the value added services for customers which includes discounts, additional benefits such as counselling (https://www.zoctr.com/value-propostion). As mentioned in the website of Zoctr they also provide options for personalized plans along with patients. Indeed the company also provides an option of shopping cart for customers to estimate the cost of services opted (https://www.zoctr.com/shopping/cart)

Thus the companies provide an elaborate business model and also runs on similar mode of other internet technology based ventures. It is noteworthy that a significant portion of the care giving industry is run on entrepreneurship model initiated as business start ups and eventually growing. These owners are

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individuals or group of individuals who have followed western model of creating profitable business out of need for home based care. Many of the entrepreneurs have noted that India is showing a high need of care at home as large number of population is chronically ill, disabled, and elderly. Many a times they prefer health services reaching their doorsteps as long term hospital based care is highly expensive. Thus they affirm home care providing affordable care and at the same time enhancing as a successful business idea boosting economy of the country (http://www.businesstoday.in/magazine/features/entrepreneurs-eye-ventures-in-home-based-medical-care/story/202279.html).

The other feature of his entrepreneurship model adopted by the owners largely is expansion policy(Annexure 13). They don't function only in one state or one city. Majority of these groups have expanded into metropolitan cities. The highest numbers of them run their services in Chennai, Bangalore, Delhi, and Kolkata (http://www.businesstoday.in). This indicates gradual growth and receptivity of care industry in major cities of India. The services indeed are expanding to other major cities such as Bhubaneswar, Pune, Hyderabad apart from four major centres as reported by both Portea Health care and Heritage Health Care India (http://www.portea.com/about-us). Apart from geographical expansion, the private sectors have also been deliberating on policies of mergers.

2.2 Private Care giving Agencies

These are individual or group led companies that have built an independent industry with their own definition and range of home care services including bed side care giving, assistance in daily functions for elderly and patients suffering from terminal illnesses. This section looks at private companies that are directly selling its services to its customers. Since 2013 there are many private hospitals and foreign based companies that have started investing in post operative care, care for elderly and palliative care. The private companies established by Apollo and Max are used here as examples to understand the model of working of these companies. The details of Max are given based on both primary and secondary data.

process of creating a business unit exclusively for home care by a hospital. Apollo Hospital in this context has created its own packages to offer. The Apollo Home Care is an extension of the existing care programs of hospital (https://www.apollohospitals.com/patient-care/value-added-services/apollohome-care). This has a management authority and range of services that have been delivered through a home care package. The functioning and the business model resembles to that of for-profit health care companies. The hospital provides customized services through an online portal or a helpline. As it states in the vision that the dream is to create an international standard for home care and to reach as many clients' home as a business proposition, a large number of management staff at the hospital are from business and management background (http://www.apollohomecare.com/about/leadership). Apart from this Apollo also has attempted in creating its own unit for home website) health care refereed in the (complex care as (https://www.apollohospitals.com/patient-care/value-added-services/apollohome-care). Max is one of the leading private hospitals and have also extended its services packages for home care. As looked into websites of other leading private hospitals there is no direct management of home care or any mention of collaborations made for such care giving purposes. Out of this, St Stephens Hospital is also one of the private hospitals that have been dealing with home care for their patients. Both the cases of St Stephens Hospital and Max Hospital will be detailed in the chapter as case studies. It occurs that the number of private hospitals in direct care giving is lesser than the for profit companies. However the for profit sector works in close coordination with private hospital in terms of funding, to cite an example Max Hospital network has been supporting Portea Home Health Care (http://blogs.reuters.com/india/2014/02/05/health-start-ups-tap-indiasgrowing-home-care-sector). In turn the hospitals which have extended their home care services also follows the business model of for profit forums and thus opts similar modes of operation. The only difference is that of sources of acquiring client which is an added package to institutional care in case of private hospitals offering services to their patients.

The website of Apollo Hospital was searched to draw an analysis of the

Max Hospital is one of the private bodies that have started its own home care packages rather than involving a third party. The Hospital still has ties with a company called Shine and Standard, however the authorities at Home care Unit of the hospital also has a say in running the program. The Shine and Standard Company is actually a cleaning service and they maintain the home care givers logistical and administrative responsibilities in the hospital. They are not the decision making authority regarding services or work profile of these home care aides but are responsible for their payment and management of account and administration along with housekeeping staff of the hospital.

Max hospital prides itself to be one of the pioneers in creation of home care networks by private hospital. The marketing of their work takes place through the home care unit. The pamphlets about the program are made available at the home care unit counter for all families attending patients. This counter at the hospital provides information and also markets the whole concept of care to its customers. The negotiations for better price also take place in this section of the hospital.

"The home care unit is working for promoting Max hospital's home care. We speak to clients whenever they come to us with a need. Many of our patients call back for home care after their release from hospital. We also negotiate for any other additional services that involve care attendants. This also includes care givers while they stay at the hospital. Our care givers are called GDAs (General Duty Assistant) as they provide generic responsibilities of taking care of daily activities of patients." Tamdin, Public Relations Department, Max Hospital

2.3 Foreign For Profit

Globe Bonitus is a Sweden based company that has invested in India in health care sector. It has introduced two layers of workforces in their organization, namely the supervisor and the care provider (www.zoominfo.com/c/GLOBE-Bonitas/367208691). As an agency it has been trying to build a market in posh localities of Delhi and hiring trained personnel from NISD. These care

workers are segregated based on the level of education and their performance in interview. Again in their case the supervisors are supposed to create documents and assist the care givers execute on ground.

The company is a Swedish-Indian venture that aims at providing geriatric care. As their focus is primarily geriatric care they hire care givers specialized in the same. The company also provides orientation training and has a hierarchical structure of functioning. They generally have supervisory level to help and assist care aides. Apart from that there are also units managing human resources, administration and finance.

The owners of the company visit offices in India occasionally for monitoring and training purposes. As far as management in India office is concerned, that is managed by the staff hired. The company has opted for public-private partnership model and collaborated with NISD for hiring resources. These groups of managers have a different set of qualifications, and are trained for managerial positions. As discussed above the course at NISD also has options of being involved at the stage of policy making, research and administration.

"There are two categories of workers in Globe Bonitus, both at the level of supervision and of Geriatric Care Provider. The first level of work needs more qualification and they have hired those who have been trained in long tern courses that provide specialization in policy making and counselling. However while recruiting they also opted for few trained bed side care workers who had higher educational qualification for supervision. The task of the supervisor is here to mainly ensure that the cases are being handles correctly. They are responsible for managing geriatric care aides and also to ensure creation of personalized plans for taking care of elderly along with care aides. They also need to document work of care aides. The basic difference is that the supervisors are not supposed to provide direct care but help care workers to provide care"- Nitu, Supervisor, Globe Bonitus

As a private agency Globe Bonitus also have paid enormous attention to customers' satisfaction. Apart from the skills of bed side care giving which is managing of daily schedule of client, the care givers are taught in great details about behaviour, skills of building companionship. The supervisors as well are trained in marketing so that they can maintain better customer relationship.

"The company owner and trainers have come twice and trained us on how to maintain documents and take care of elderly. They tell us about behaviour, companionship for elderly and how to manage the daily routine. They share how they would want to have more and more clients. They also discuss about marketing of the concept and how managers, supervisors and care workers can contribute in maintaining a god customer relationship. For this they teach communication, relationship management." Neera- Supervisor, Globe Bonitus

As home care industry is growing, the challenges of running home care work in Delhi are also increasing. They shared how it is although a very lucrative market but often it becomes difficult to ensure that care givers are taken professionally by the families. The company further shared that they still are planning on executing home care project in Delhi and other cities in India as they firmly believe that it will reap financial benefits for the company and also will tackle the issue of care gap.

2.4 Placement Cells

The placement cells are important part of care giving industry. Primarily the placement cells were engaged in providing services of domestic workers. This has focused on the migrant population from different states who can serve as domestic maids in urban spaces. These cells have extended its services to providing nurses as well as care givers owing to the need of care at urban homes. As derived from web analysis of 66 such websites listed on one of the information portals, they have been proactively engaged in providing more than one health services at doorstep (http://yellowpages.sulekha.com/home-health-care-services). If one closely looks at the nature and type of such placement cells there is a need of looking primarily at the ownership of the business and who manages such structures. Secondly there is a need to

understand that since when the placement cells have entered into business in health and also the collaborations they have to promote their businesses. Finally the section will also look into the kind of services provided by these placement cells and how these have defined the whole aspect of home care. There is a need of further exploring into the rules and regulations around creating of home care aide for bed side care giving and how that service is designed in this context.

a) Ownership of the Placement Cells

The placements cells are primarily are privately owned entities by one person or a group. There is no registration record available at the website for the placement cells. As derived from the information available on 66 websites listed on sulekha.com (http://yellowpages.sulekha.com/home-health-careservices) the management available consists of one or two persons who work also as a connecting dot between clients and the care givers. The other type of staff consists of the people who are handling direct services, care aides being one of the positions. As far as registration of such placement cells is concerned there is no concrete data on the same available on the webpage. The placement cells have registered their services on these web pages citing and detailing the information on their services. There is no clear indication in terms of their registration number or any reference to laws of business regulation under which they may have been registered.

The placement cells have used common business information websites (Sulekha.com, indeedjobs.com) for promoting their work. The information on placement cells is classified along with the other business endeavours for home furnishing, hotel businesses. This implies how home care giving is flashed out as a product. Thus these websites also provides space for reviews on services, negotiation space and also business quotes. The placement cells usually do not have any business websites and use these pages which promote business for generic products. These online forums are primarily collaborative platforms for individual business ideas where they can register easily and start marketing and selling. In fact the placement cells also have tried to customize

their services through these web pages. In this a client can browse for the services needed with advanced search options.

The placement cells have been playing an important role in creating health care aides for nursing and home based care giving. The cell that has been covered in this study is located in the area of Ashram in Delhi and it has been functioning for 10 years since its inception. The owners of the placement cell have clinical background and its genesis can be traced back to demands put forward to owners in the hospital for home nurses. Thus the services provided at primary stage were that of nurses. However gradually clients started demanding for bed side assistance and thus the agency started employing nurses who were willing to perform both kind of work. However it was not a pragmatic solution as the nurses refused to perform any lower skilled job. Thus a fresh recruitment began for the cadre of home care givers. The placement cells used contacts from nurses for such recruitment. As shared most of the care aides recruited initially were from hospitals working as ayas or cleaners.

The placement cells use terminologies like Home care attendants, Patient attendant, General Duty Assistant, Bed side assistants when it comes to bed side care assistance. The work of nurse also falls under the category of home care; however they are distinct from bed side care givers in terms of profile of work. As far as marketing is concerned unlike what has been found in the web analysis report the agency directly builds connection with hospitals and takes help of nurses appointed to get more business for such work.

b) Varghese Placement Cell

The placement cells have been playing an important role in creating health care workers for nursing and home based care giving. The cell that has been covered in this study is located in the area of Ashram in Delhi and it has been functioning for 10 years since its inception. The owners of the placement cell have clinical background and its genesis can be traced back to demands put forward to owners in the hospital for home nurses. Thus the services provided at primary stage were that of nurses. However gradually clients started demanding for bed side assistance and thus the agency started employing

nurses who were willing to perform both kind of work. However it was not a pragmatic solution as the nurses refused to perform any lower skilled job. Thus a fresh recruitment began for the cadre of home care givers. The placement cells used contacts from nurses for such recruitment. As shared most of the care aides recruited initially were from hospitals from those who were working as ayas or cleaners.

The placement cells use terminology "home caregiver" when it comes to bed side care assistance. The work of nurse also falls under the category home care; however they are distinct from bed side care givers in terms of profile of work. As far as marketing is concerned unlike what has been found in the web analysis report the agency directly builds connection with hospitals and takes help of nurses appointed to get more business for such work

2.5Private not For Profit

As opposed to privatized network of care giving agencies, the philanthropic organizations and the NGOs are adopting different methods of recruitment. As indicated from the web search there is not much evidence of this type of institute recruiting through such portals. These institutes rather work in a charitable mode and adopt model combining clinical practitioners, social workers, nurses volunteers and family members. As reflected from the information on website the other jobs such as marketing and promoting this kind of palliative care is not given planned attention (. The model is service oriented and generally it can be deduced that it works on the premises of team building for palliative care methods as indicated on most of the palliative care literature. The NGOs or the philanthropic organizations that have been registered as societies (Societies registration act, 1863) or trust act as trusts also distances itself from a commercialized model and focuses on the part of nurses and doctors and social workers. The model as it seems however lacks the presence of care giver as a separate entity and most of the tasks is carried out by the clinical bodies which often are disdained by them. There are only a few organizations that have paid attention to building specifically care givers for long term home based care.

There are certain NGOs and philanthropic bodies that pay attention to home based care. Can Support is one which aims at providing care to terminally ill patients after a point when the home environment is considered best for the person. The websites of Can support informs that 25 teams comprising of health care aide, counsellor, a doctor and nurse have been formed. The model opted here is based on models of palliative care also discussed in previous chapter as part of review. There are other NGOs as well such as Caring Heart, Cancer Patients Association, and V-care who follows the same palliative care model of having a team for such care. They primarily work in reference with Shanti Avedna (http://www.shantiavednasadan)

2.6 Training Institute

These are institutes that have a model of providing training to health care aides and place them either directly or through other agencies. There are both governmental and non-governmental institutes that fall under this category. In this scenario there are two organisations that have been covered in the study which are St Stephens Society and NISD. For St Stephens and NISD both primary and secondary data have been used.

St Stephens Society started its post clinical care in their hospital long before the whole aspect of the home care giving began. The website of the Society indicates that it began working on care giving for new born babies in their hospital (http://www.ststephenshospital.org/). This paved the path for new concept of home care which was flagged of by the Community based organization built under the aegis of the hospital. The main architects of the whole concept of home care were founder members of the society and the doctors of St Stephens hospital. They had realized the significance of home care while interacting with their patients. The home care unit began in the year of 2005 hoping to meet the need for post institutional care and also to engage women from one of the communities in employable opportunities.

"The need was already there as we would get request from patients at the hospitals for ayas or someone who can help them takes care of patients at home. There was a massive need felt at that time, so we began our process of training care givers. To give it a personalized touch we renamed her as Bua, and we began the process along with our community based organization which was already involved in creating livelihood for women from the community. We realized this could help women from the community. So we began meeting and also Doctor John had started creating modules for care giving work. We had invited women from the community and also had multiple meetings. We were convinced about the need of such work and that it can provide better opportunities for women in Sundar Nagari Community." – Doctor Anita, Trainer for Health Care Aide, St Stephens Society

Doctor Anita further shares that this initiative has changed many lives of women living in SundarNagari Community. She counted it to be pioneering initiative of St Stephens Society in the arena home health care as well. She further adds that as it is important for the community to be part of this pro-actively, the organisation is completely bestowed managerial and operational tasks to the women empowerment groups of the NGO. This group is a cooperative or a self help group that assists women form the community to build on their aspirations. As this is one of the pioneering institutes in training health care aides, the designers of the program has created their own functional definitions and job profiles for the health care aides. The doctors at the institute further add that a lot of definitions and terminologies are derived from the palliative care work.

The definition of home care services here in the context of St Stephens sticks to bed side care assistance. The care givers in the initial stages have taken care of the post clinical but institution based care giving in St Stephens hospital. Although there was no bifurcation between the care aides working in institute and at home, later both the categories were segregated. As stated by one of the doctors, although the kind of work was same which is to take care of activities of daily living, it became complicated for the whole intervention to manage care aides doing both kinds of work at the same time as home based care would need more

attention and time. Thus the profiling changed and the women were recruited specifically for home based care.

The care givers unlike what has been discussed in case of comprehensive care network, assistance for elderly or ailing only becomes one part of the entire foray of services, whereas the nature and extent of care provisioning in this case is exclusively activities of daily living at home. These range of ailments or issues are multiple such as taking care of elderly, chronically ill patients and dementia patients. This category of workers can be called live out health care givers (the terminology used in this scenario) as they provide hourly services and not living in facilities. The category of live in health care givers is common in case of placement cells which shall be analyzed with the case study of placement cell. Although there is no detailed information on live in or live out categories in case of website information of placement cells, live in facilities is available as derived from data analysis. The other significant aspect of this training initiative is that it does not aim at high end profit generation or are business oriented. It is much more concentrated on livelihood generation out of care need that is generated in the society in recent times. Thus although St Stephens Hospital's doctors and the women trained are part of hospital's care network, there is no profit sharing with the hospital which is a private entity. This category of care giving is however distinct from that of philanthropic movement which is much more focused on patient's care rather than economic growth of givers care.

> "We decided to go with the option of women from the community of Sundarnagri as the work could really benefit them. So we went to all the women and convinced them about this concept. It was not an easy job as there is always a stigma around the whole aspect of doing this kind of work which involves wiping of patients bodies, bathing. It is difficult for them to cope with such things. It took a while for us to prepare the community for the same. Although few dropped out many stayed in and our training began and soon we began employing our

care aides"-Doctor Anita, Trainer for Health Care Aide, St Stephens Society

The second aspect that needs to be reviewed is the processes and challenges that have been encountered by the care program in the initial stages and how the whole concept of care work grew in the context of NGOs. As is reflected from those who were involved from the beginning the demand was always there and it was growing anyways keeping in mind the rapid urbanization. The proliferation of market was not that much of an issue as there was number of contacts from the hospital which helped in building a market. At present the customers get to know about the work through word of mouth, network at St Stephens Hospital and also previous clients.

In the initial phase most difficult part was to handle clients as they had a very different attitude towards care givers. They would consider it as lower skilled job and hence would equate it with the job of a domestic maid. This made it very difficult for them to bargain price as well as ensure the care givers are treated well in the workplace. There were not many contenders in the market in the beginning but as the number of providers increased the durability of job declined.

To discuss the first point there is a need of reflecting on what has been shared by the key informant i.e. the managers and trainers of the unit. The initial process of dialoguing with the clients were primarily of two kinds, one was to negotiate and fix pay and secondly to reduce prejudices the care aides possessed about the work of care aides.

"We have had major issues dealing with clients, specifically when it comes to negotiating the wages of care workers. When we began not many were aware of existence of any such work and often would consider it equivalent to work of domestic maid. Thus there was a need of changing whole scenario of how this kind of work was looked at. We put a lower price for the work of care givers when we began. Gradually things have changed and thus the challenges of increasing the wages of the women have become possible" — Nitu, Manager, Health Care Aide Program, St Stephens Society

The designer of the program admits that there is still a challenge in maintaining regularity of the work as majority of the clients want a care giver for not more than few months. There are fewer incidences where care giver is kept for more than a year. It becomes a difficult reality owing to two issues one is that of the chronically ill patient are mostly terminal.

As it grew to be a fully fledged unit, it also had certain kind of structure to run the entire system of delivering care to families. There is a hierarchy and it composed of people from both community based organization and doctors from the NGO, as well as those who are involved in the services of St Stephens Hospital. Diagrammatic representation of the same will be three layered as the authority of the hospital and the NGO are also part of training and running or supporting of the unit. The hierarchical structure showcases that the home care workers are at the lowest bottom and the decisions about their work is primarily in the hands of these joint forum of NGO, Hospital and the manager of the CBO who also looks after other livelihood programs run by them.

2.7 National Institute of Social Defence

This institute (Annexure 6) has been working closely as a part of the Ministry of Social Justice. The genesis of the institute is rooted in decisions made by government to create more supporting systems for elderly in national Policy for Older persons (1999). In this process they had recognized the need of more Human Resources and thus the institute was given responsibility of training and research. There is a need of looking closely at the structure of this body as well the collaborations they have made in terms of home care giving. The training provided from this institute is specialized as they are providing care particularly for elderly. As derived from web analysis they envisage creating more resources for helping elderly to cope with ailment and loneliness thus the whole course comprises of counselling techniques, information of anatomy, information of terminal illness (to take care of elderly suffering from ailment) (http://www.nisd.gov.in/content/128_1_OldAgeCare.aspx). The institute believes for a home care giver such information is needed as they help them

provide much specialized care. They also have multiple layers of training program for care givers as within the ambit of care giving to elderly they have focused on creating multiple layers of care providers both for policy and research and direct care giving.

Firstly the unit of NISD is known as centre for old age care. The General Council of the government is the main body that comprises the Secretary, Ministry of Social Justice and Empowerment, as its ex-officio President, there is an executive council that takes care of the implementation part of the program (http://www.nisd.gov.in/). The functional unit of old age care has trainers in place that takes care of capacity building as far as home care is concerned. Mostly professionals in the institute are from research background. Both the trainers' positions are filled with professionals with expertise in health and psychology. As shared by key informants the criteria is that of specialization in health sector. The institute prefers a doctorate degree as they also provide high skilled courses for geriatric policy making and research.

Now as far as the caring is concerned there are two different kinds of courses which define how they perceive the work of care workers. They have conceptualized care giving in two ways, one is carried out by front line health workers who are specialized in geriatric care and can contribute towards public policy and planning as well as research (http://www.nisd.gov.in/). This course is much more focused on creating health care workers who are specialized in counselling techniques, can draft better systems for geriatric care both at home and institutes. The other layer of training for care giver, the institute provides is that of professionals from NGOs or day care centres for enhancing their skills.

The second definition of home care pertains more to lesser skilled category and hands on work for taking care of elderly population. The institute uses the terminologies care givers or bed side care givers for defining this cadre of workers. They are supposed to pay attention to bed side assistance, palliative care and emergency care provisioning. This category of care aides are required to have the lower level of education than previous two and this is more of a practical work as shared by the trainers of the institute.

"The bed side care giving is an important aspect in the whole paradigm. But this is a low skilled job and lesser paid therefore the training comprises of practical experiences of interacting with community with basic knowledge of anatomy. This is followed by internships in hospital which helps the students realize the pros and cons of care giving".-Doctor Sunita, Trainer, NISD

The training profile of the care workers is changing with an evolution in care industry. As customer satisfaction has been uttered as a motto in private domain which has a strong presence in the care industry, the institute also has been training their cadres in client management, hospitality and companionship at present time.

Notably, although the agency is governmental, its role never has increased beyond that of provider of human resources to regulatory body of care networks. Indeed promoting the market oriented approach of the private sector it also has been paying attention to collaborations with the private hospitals and agencies.

"We have connected to many organizations this time for placement. We think it is important as it increases marketability. Right now majority of the work is being provided by private sector. Recently we have been able to create collaborations with Max Hospital for employing our work force. This is important for us as our aim is to increase the number of health care aides for elderly. The private hospitals are at present getting highest number of patients in urban spaces and thus networking with them is really required. They also are showing lot of interest which is good indication for future scenario of care for eldelry" – Doctor Sunita, Trainer, NISD

There are certainly other collaborations with government hospital and also non-governmental organization but as shared by the key informants the need of the hour is to create more opportunities for those who have applied for the course as the motto is to increase human resource for elderly care. Thus it becomes really crucial to ensure that the trained workers are getting employed in different institutes. Moreover as shared the private sector is

the most important player at the moment; hence most of the care aides get into private sectors.

"It is a lucrative and booming industry and it can pave path for employing opportunities hence there is a need of joining hands with private sector. Public Private Partnership will be extremely effective in this case and the care gap will be resolved by leaps and bounds in India."Doctor Anindita, Trainer, NISD

Indeed there is a firm believe that care gap and need for caregiver from outside for bed side assistance would increase in upper middle class and upper class sections of the society. There is a specific demand from the NRI section as well and thus the current trend of privatization and need of well groomed care aide is much needed at present

3. The Allied Agencies

The allied agencies are primarily online portals and also organizations that have been extending research and counselling support to families and care aides for providing better care at home. These fall under public, private and public private partnerships typologies. There is a need of discussing the kind of portals that are present, their genesis, the number and nature of their working. The section will also explore into kind of information provided to care aides through website material, online consultation and workshops.

There are online portals that give information on how to take care of elderly, chronically ill patients and on issue of dementia. These portals although have similar purposes but the nature of functioning, the marketing strategies, targeted clientele, kind of support extended are different from each other. The first sub category under consultancy group for profit category are online forums that gives information and assistance to family care givers, the second subcategory is that of organizations that promote research and training for post hospital care and well being, assistance for older age and mental illness,. The third category is that of foreign companies who have been involved in research and care area. These are also companies who are apart from direct care giving

and home visits, help patients maintain medical records and personal details of health through online portals that is easily accessible to care givers in family.

Similarly in public sphere there are government institutes which are involved in research related to care and trainings of the care aides. There are other institutes that provide space for internship and capacity development of care aides. The third category is that of public private partnership bodies that consists of non-profit organizations and institutes that provide information and advocates for quality care provisioning at home.

As care giving industry is making its progress in Indian context there are online platforms which have recognized care giving as a skill. The online training programs for care aides is something visibly present in western context, however it is also catching the momentum slowly in Indian market scenario. One of the most interesting facts is of involvement of state in skilling and providing capacity building for the purpose of home care. In this regard there is a need of discussing about the skill India campaign which covers home care as well apart from other kind of services.

Under this campaign there are private institutes that have designed courses for multiple paramedic streams. One of the private on line universities linked to skill India program have been offering the course for health care assistant that entails the functions of either bed side care giver or someone who can assist elderly and ailing. (http://www.vishwakarmaopenuniversity.org).

There are few organizations that have been focused primarily on research and advocacy for better care giving that shall be discussed as a part of chapter. The typology of such organization is somewhere between public and private. The genesis of the organization can be traced back to 1984 and the society has been dealing on the subjects of awareness generation, creation of support groups, help lines, doctors' visit and information about various clinical and counselling services for Alzheimer and dementia (http://www.alzheimer.org.in/chapters.php). The institute acts as a knowledge bank as well with its research wing on need of post institutional care for dementia. Apart from this the public hospitals such as AIIMs is also

contributing towards creation of knowledge and resources related to geriatric care (http://www.aiims.edu/en/news/95-geriatric-medicine.html).

Like other portals there are also online advertisements sites that provide information on availability of home care services in Delhi, help lines that can be connected for services. These are generic websites that provide space business groups to promote business ideas as well as to hire human resource (http://www.indeed.com/q-Caregiver-l- Delhi,-CA-jobs.html). This also helps families to look for individual care assistants or find a source that can provide a contact (http://www.indeed.com/q-Caregiver-l-Delhi,-CA-jobs.html). There are few websites such as "quikr" that also have listed care giving at home along with selling of home care appliances, housekeeping and domestic maid (www.quikr.com).

There are other marketing and selling websites that provide space for home care as a product to be sold. Out of these sulekha.com and yellow pages have information served on home care giving (http://yellowpages.sulekha.com/home-health-care-services). The role of such websites will be discussed in the section of placement cells as these mainly promote their business.

The public hospitals as is reflected from their websites do not generally provide a long term or short term operative care owing to lack of bed, human resources. However there is an evidence of them being involved in both acting as mediators for care giving as well as building resources related to care. The web analysis on AIIMs, one of the premier institutes for health showcases its participation in research related to geriatric care. The institute has prepared manuals and documents for older population to stay healthy. This also comprises of materials for nurses, care givers, community health workers and families to ensure better care for elderly (http://www.aiims.edu/en/news/95-geriatric-medicine.html). As far as direct care giving is concerned some of the tertiary care hospitals have created ties with placement cells/ NGOs/companies. These collaboration are of primarily two kinds; one in which the public hospitals take interns and training attendants from other institutes in which they connect their patients looking for services to placement agencies

and companies . In this way they have been tackling the problem of lack of manpower for tertiary and rehabilitative care in post clinical phase. For the second kind hospitals primarily work as a network between placement agencies, NGOs or for profit companies to connect to families who are in need of care. In this way they also help increasing employability of the care assistants. This is derived from the discussion with training institutes and care aides working through placement cells that have tie ups with public and private hospitals. The first category here is that of those institutes who have collaborated with an NGO/placement cells to completely take charge of section of post operative care or care assistance. In this context hospitals such as AIIMs have been creating space for NGOs to support senior citizens to provide post institutional care, which includes re-visit of doctors, getting appointment details, managing records or finding services within the hospitals. This information is derived from the interviews with the staff employed from Help Age India an NGO that has collaborated with AIIMS for providing assistance to elderly. Although this is not directly linked to home care it helps patients through a helpline available to get information from home as well. They have also been working informally as a unit for suggesting options of home care providers if needed.

Apart from this there are also Municipal Hospitals, catering to secondary and tertiary care has no exclusive programs for rehabilitative home care. However some of them have collaborated with placement cells, NGOs and other institutes for the purpose of providing after- institutional care. One of the initiatives that have been taken by Ram Manohar Lohia Hospital is that of training programs run for care attendants. Ram Manohar Lohia has associated itself with governmental institute of training. As derived from interviews conducted with key informants of Geriatric Care Unit of National Institute of Social Defence, Raja Ram Manohar Lohia Hospital has been providing space for internship of bed side care assistants. This in turn has motivated families to hire these trained workers for home based care work.

"We generally send our trainees to RML or AIIMs for internship which is mandatory to understand the practical nature of care work. This exposure training program is particularly for those who are into bed side care giving. Although they are not allowed to work as home care giver during the process of internship many of our bed side assistants have been asked by the families to work at home to look after patient. Few of our students have also opted for that for few months." Doctor Ainidita, Trainer, NISD

Similarly there are private hospitals that have been taking similar steps of forming collaborations with other placement cells and work as consultancy or Network agencies rather than providing direct care to patients. In this scenario again the type of service provider can range from placement cell, NGOs to training agencies. The web search depicted that private hospitals such as Forits and Mool Chand Hospital do not have any such home care unit. (http://www.fortishealthcare.com/india/patient-care).

They discuss patients' about right for good services (http://www.fortishealthcare.com/india/patient-care-and-services/patientattendant-rights-4) in the institution and also have range of packages with health facilities but have no mention about home care facilities. Again as derived from interviews with key informants of placement cells and independent care providers, such hospitals have connections with placement cells, profit oriented companies, independent care workers who can be connected in case patents require home care services. The profitability of such hospitals in this case cannot be determined on the basis of web analysis.

The hospice care movement in India also had begun much earlier than commercialization of care work. In this context the philanthropic institutes have been involved in not only providing direct care assistance through care centres but also they are vehemently associated with research and assisting family members for better care giving.

The underpinning of such movements had been very philosophical in nature. The movement also began as a need was felt by medical fraternity of tertiary care institutes for rehabilitative support system for patients (http://www.cankidsindia.org/milestones.html). The example of Can kids, a hospice centre can be shared here. The genesis of the institute can be traced

back to care gap that was noticed in public hospitals by doctors at AIIMs. As far as the nature of financial sustenance is concerned, as it does not derive profit from home care or care giving, the hospice movement has created a network of support for sustaining themselves. Indian Cancer Society is a public trust that has been supporting comprehensive care on cancer (http://www.giveindia.org/m-1588-indian-cancer-). The trust has been crucial in providing financial assistance to hospice care centres. It is noteworthy that the hospice care centres also depend on individual donations which are used as corpus fund that maintains the institute.

As far as the training and capacity building institutes are concerned there have been governmental institute which has already been mentioned before, provides training to care aides. They have been collaborating with private institutes in order to create employments for this trained cadre of workers. There are also institutes that have been associated with training and workshops and are collaborating with public institutes. To cite an example the intervention of ARDSI (http://ardsi.org/ardsichapters.aspx) is important for discussion in this context. This is one of the research and advocacy institutes which had been working in collaboration with various governmental organizations for making training and policy purposes (http://ardsi.org/ardsichapters.aspx). This falls into the category of Public-Private research and advocacy institute. They also talk about a more regulatory space and adequate state engagement as opposed to private spheres indulged in care giving.

ARDSI for example in its websites entails that policy engagement should be with state to ensure better care for elderly. It also has engaged in the five year planning processes for better policies on dementia care specifically during elderly phase. The institute also has taken into consideration collaboration with many state and district agencies for training, workshops, interactive sessions and also regional resource centres promoting knowledge on care giving for dementia patients. (http://ardsi.org/wedemand.aspx). The other primary institute which has also focused on capacity building for research in palliative care is the Non Profit organizations that are providing day care and consultancy care to families and hospitals, institutes such as Can Support

provide such assistance. The hospice care centres are regulated bodies and are mostly registered as trusts or societies under Societies registration act 1860 or Trust act. This also implies that the organizations are working as not for profit ventures as they are registered under aforementioned laws.

The other platforms that deliberates to some extent on home health care in India are the National and international news dailies, websites and blog reports. From web analysis many options were found where the organizations, online forums, business dailies have been closely monitoring the rising need of care at home, growth in elderly population and most importantly the expansion of home care as an industry. In fact these provides very significant information which helps in understanding the financial boom that the whole aspect of home care brings to health care industry in India. The Economic Times had covered extensively on the fiscals of home care as a business. It discusses on the absence of care also in small towns specifically for elderly and how the need of getting paid care is essential at present time and the role of the industry is increasing the revenue. According to this report, one of for profit companies and earliest player in this industry expects to touch an amount 20 Crore as benefit since its inception in last 3 years (http://economictimes.indiatimes.com/small-biz/startups/). It further states that globally home health care market is estimated to cross \$ 300 million by 2018, whereas the market size in Indian context would be around 12,600 crore (http://economictimes.indiatimes.com/industry/healthcare/biotech/healthcare/c hanging-demographics-fuelling-demand-for-home-healthcare-lack-of-medicalcare-in-smaller-towns-responsible/articleshow/33755782.cms). Some of the reports further states how provisioning of varying range of care at home including bed side assistance has helped in avoiding expensive institutional care. This indeed has acted as one of the main selling points for the profit making home care agencies as home health care is accounted as 90% cheaper than hospital care (http://indianexpress.com/article/india/india-news-india/fora-few-bucks-more-now-get-healthcare-at-your-doorsteps/). Many such other reports and blogs exist on web that looks into the reasons of this expansion. Interestingly the discussion on home care in business circles also have reached to universities that offer management courses. One of the blog reports by business management department of University of Pennsylvania reinstates the cost effectiveness and better results of home care for patients in India. It states as a country with growing ageing population and chronically ill patient, home is solution care the best to ensure better care (http://knowledge.wharton.upenn.edu/article/home-health-care-india-searchright-business-model/). Although there is not much academic research around the issue of home care these reports provide evidence as how with the growing number of elderly the demand and subsequently network of care providers are increasing both in organized and unorganized manner. The number of agencies that are providing direct care is also increasing gradually. As the market predicts huge profitability, there is a need to understand the roots of this industry, the great influence of private sectors and the mushrooming of both organized and unorganized companies.

4. Growth strategy for Private Sector

Foreign investment care agencies:

Given the fact that there is a growing demand for care at home as well as the whole aspect of post institutional care or home care is being discussed also in research or project initiatives in other countries, there are few foreign companies that have began its business ventures in India in home care industry. As estimated in a web report the home care business is India's home which consists of home-based medical devices and home care services, is worth \$2 billion and growing at 20 percent annually, according to accounting firm Price Water house Coopers (PwC) (http://blogs.reuters.com/india/2014/02/05/health-start-ups-tap-indias-growing-home-care-sector/).

In 2013 United Kingdom have signed contracts with government of India to invest more on health care which is both of public private nature and exclusively private. Under this changing circumstances there had been many initiatives where the foreign based companies have invested in the area of health care, post institutional care being one of the most important ones(http://www.gov.uk/government). The other areas of investment have remained hospital management, grants and capacity building for research areas.

The investment is coming from western countries gradually and the phenomenon started approximately in past 3 years. To understand the role of foreign investors in such home care industry websites were searched and it was found that although the investment by foreign companies is not excessive it has begun to surface in urban and semi urban spaces. Globe Bonitas is an Indo-Swedish venture formed to provide Geriatric Healthcare Services for the care of elderly at home (www.zoominfo.com/c/GLOBE-Bonitas/367208691). The case of Globe Bonitus will be discussed in details as a case study. The other ways of foreign investment entering India is through companies catering to NRI population. To cite an example here, Bayada agency bought 26% of the share in an India based company that works in Delhi as well (https://www.bayada.com/india/india_about.asp). As shared in one of the web reports, this is one of the best options for NRI clients who look for quality home care services for their parents. In fact there had been couple of other services which have specially been delivering care packages to parents of NRI clients (http://homecare.bhnhealthcare.com)

Derived from web analysis it can be summarized that there is online revolution related to home care that has begun in last 10 years. The web reports have increased the magnitude of industry and how it is increasing its scope every day in the context of India. It is not only a feature of the metropolitan cities but the services are gradually penetrating in to semi urban spaces. This also reflects how home care services has become predominantly a contracted out service supported and nurtured by the private as well as government hospitals. This online forum as is claimed by the companies is making the health services just a click away; however there is a need to understand if it is accessible to all. Owing to the high profitability earned it can be derived that services are expensive and caters to a high end section of the society.

4.1Mergers and Growth

These ventures created by groups of professionals or individuals also have caught attention of bigger companies and foreign investors. A business blog further states how the bigger companies have bought shares from such start ups to create bigger investment. Indeed there are also brands such as Dabur

who has now invested in the market by merging into business with the existing health care services (http://blogs.reuters.com/india/2014/02/05/health-startups-tap-indias-growing-home-care-sector). In this case mergers associations built with foreign investors also came as a profitable move for the industry. Delhi-based Portea Medical, received \$8 million as funding from venture capital firms Accel Partners and Ventures in December 2013. Again, Delhi-based Health Care at Home India has been working as a joint venture between the UK's Healthcare at Home and the Burman family (http://blogs.reuters.com/india/2014/02/05/health-start-ups-tap-indiasgrowing-home-care-sector/). These mergers not only have been boosting finances of these companies but also acting as approval and brand factor which is very crucially placed in home care industry at the moment. This has been turning home health care completely into a commodity with involvement of large business firms. As home care market is growing extensively on the model of entrepreneurship there is also a business rating of services in terms of investment. collaboration and profit made

The other players that are important in the context of privatization of home health care are private hospitals and placement cells formed in various cities to serve the purpose of care work. Secondly there had been a few non-profit organizations and community based organizations that have paid attention to care work on account of creating more employment options and also to bridge the care gap. The following section will look into role of private hospitals in extending post institutional care followed by role of placement cells in enhancing its role as an industry. As opposed to privatized nature of home care it will look into conceptualization of care- giving when it comes to non-governmental organizations and public- private sector.

(https://yourstory.com/2016/05/house-healthcare-startup/).

Conclusion:

To conclude it can be stated that the care giving industry is expanding in context of India. There are however many stakeholders associated in the growth of care as an industry both from private and public sector. The care industry also shows a promising growth and profit for private companies,

hence it is also witnessing good amount of investment from bigger private hospitals as well as foreign based companies. It is important to understand the kind of placement patterns of this agencies and the nature of recruitment of health care aides and other workforce to support the industry which is discussed in the following chapter.

Chapter 4

Position of Health Care Aides in Industry, Hierarchies, Placement Strategies

This chapter will delve into placement patterns, recruitment of the care aides and also the provisionary. It is interesting to understand the background and intention of the care provisionaries and how and why they played a role in the commercialization of care giving. It is important to understand the placement processes and the hierarchies within such organizations, the sources and methods of placements in the context of the huge commercial venture. This chapter will look at placement patterns across all the segments mentioned in the previous chapter namely private, public and public private forums and the philanthropic institutes, hospice centers. Web based data on placement techniques, hierarchies and socio economic characteristics of this categories and its role in placing workers in different positions shall be analyzed alongside field assessments.

1. Private Bodies

These private bodies comprise of the domestic and foreign based companies as enshrined in the previous chapter. The following section will discuss about placement patterns followed by the private care giving organisations both domestic and foreign respectively. For this purpose both primary (web based data) and secondary data are used. The placement pattern will be analysed based on the procedure of placement, sources used for hiring health care aides, any other kind of workforce is hired for the purpose of managing the various other function of the agency, positioning and importance of the health care aides in this process.

1.1Domestic Companies

The domestic private companies referred here are Max hospital and Apollo Home Health Care. The researcher observed based on primary data collected from Max hospital and also secondary review of web based data for both the organisations.

Hierarchy in the workforce exists in private domestic companies. This is evidently seen in the structures followed. As this has been developed as a commercial concept the industry, the private companies are paying a lot of attention in hiring or organizing the management bodies for the whole care aide business

As reflected from primary data, the private domestic companies such as Max health care company of the hospital generally has an HR department at the top to manage human resources. However it is not an exquisite department only for the purpose of care aides and thus the larger network of managing talent and resources also looks at hiring of care workers. Similarly the information available on the website of Apollo Home Health Care also suggests that other work such managerial ranks and other kind of skilled services for home care is such as physiotherapy, nursing are hired for the purpose of maintaining health care industry. (https://www.apollohospitals.com/careers/) Among this category of workers hired for homecare, the managerial cadre plays a very important role in managing the business and enjoy better position and pay. It is very important to understand the back ground and qualification of these managerial categories as well who enjoy better privileges and job securities in comparison to the health care aides. Indeed one of the supervisors from Max Hospital stated the following

"The health care aides are the lowest rank in the company. Mostly it is the higher authorities who make decisions on how much to be charges form patients. My duty as a supervisor is only to follow this whole hierarchical order and keep track of work of the GDAs, in terms of if they are going to work, response of the family. There is a managerial, finance body who maintains public relations and business side of the whole care giving agency."-Mr Rakesh, Supervisor, Home Health Care Unit, Max Hospital

Apart from him the public relation department of Max Hospital also reiterated the importance of the other category of workers to maintain business of care giving.

"The public relations office has a crucial role to play in the marketing of care work. We are very particular about care packages we provide to our customers. These are very important decision and the a good brand image depends on how interact with the customer group. The job of GDAs is to take care of patients, but there is lot of other work that goes into making care business of Max available to those who are seeking for it. Thus a team is necessary, and although I cannot comment that the work of health care aide harder than ours, but being a public relation person I can say that my job requires set of skills to deal with client and other collaborations. The job I have of course superior in qualification and hence require a skill full person."-Tamdin, public relations, Home health Care Unit Max Hospital.

The following section will analyze the nature of job and placement processes for the management officials, and other officials maintaining systems in the care business as well as the care aides through advertisements posted on the company's websites, common portals online that advertises for vacancies (Annexure 14). Through the advertisement portals the qualifications, background and the stake of these management bodies would also be assessed (based on job profiles).

a) Sources of Employment:

The domestic companies also have used their own portals for advertising for jobs and also other online forums for the purpose of recruitment in the field of health care. It is noteworthy that the jobs mostly advertised are for the section of care coordinators. The care coordinators however are not for the purpose of looking after care business per se but to co-ordinate appointments of the people who would want to receive care. The other categories of professionals that are hired for this job are the trainers, medical professionals that can design (https://www.naukri.com/apollo-home-healthcare-jobs-careers)

Medical Lead to overlook service delivery caregiver skill training Jobs

Responsible to create medical protocols and patient care plans. Responsible

for product development, health package development, global standards

developments. Administration of critical care and patient recovery.

Coordinate with global healthcare companies/academia/colleges and bring

best practices Qualification & Experience: MBBS with 3+clinical experience

for Medical Officer Candidates with critical care expertise like ICU,

Emergency Care etc. would be preferred Intensivists or doctors working on

offshore assignments/ cruise lines/ rigs etc will have advantage Job Activities

(not limited to)

Defining care plans for the home care patients, includes defining schedules,

interventions, parameters to monitor, measuring patient recovery Patient home

visits and phone calls for recommending as per the condition, if required

Developing standards for home care for different conditions and ailments Help

in specifying technology solutions for automations and health reports.

Developing training modules and materials for different patient care. Training

Nurses and Paramedics on clinical aspects of patient care Attend global and

national healthcare summits and represent the company's requirements

Medical Lead CTC - 6.00 - 9.00 Lacs

They offer world class care at home through their 100% background verified

caregivers which include: Nurses (ANM, GNM, Bsc) Attendants, and

Physiotherapists

Candidate Profile

Desired

Education:

Graduation: Any Graduate / Any Specialization

Post-Graduation: Any Post Graduation - Any Specialization

Doctorate:NotRequired

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Key Skill: Healthcare / Medical / Pharmacy Company Description Alloys Consulting Pvt. Ltd. is one amongst the fastest growing recruitment companies with its presence in India, South Korea, Japan, Taiwan, United Arab Emirates, Africa etc. Alloys Consulting Pvt. Ltd. has been the chosen partner to clients in providing Consulting, Staffing, Specialist Recruitment & Manpower Solutions across various verticals like Oil & Gas, Information Technology Services, Marine, Power, Engineering, Construction, Telecom, Retail and Healthcare. Our core business lies in providing end to end recruitment solutions tailored to the needs of our clients. Our innovative range of recruitment solutions helps our clients leverage their business and sustain a global advantage.

The private domestic companies also have used the job site page for advertising for jobs of care aides. The level of other skilled jobs finding its place is much clearer when it comes to The job that these companies pay much more attention to acquire through these recruitment process is actually are those who can either manage or instil more skills in the care aides (https://www.maxhealthcare.in/careers/job-openings)

. As the business requires there are other categories such as accountant's job displayed on the web portals. Generally the organizations pay more attention to hiring of the organized network of skilled professionals for the systems through online web portals. In this case the major idea is to include these set of workers to make care giving as product more efficient in terms of marketability and sustainability. The process of recruitment for the care givers themselves are not part of web portals extensively. However a noteworthy fact remains that from the side of the private companies there is an immense attention paid to managing systems for sustainability of care work as a business model. The job roles defined for these categories imply how they play a significant role in what care workers are delivering.

When it comes to background and qualifications of these set of work force it is noticeable that they are mostly from the background of management or someone that has the knowledge of health management in commercial ventures. The other essential aspect is how these networks of placements exist

also beyond hospitals network and talent hiring companies, consultancies that deal with both national and international clients are also an integral part of the process.

In similar ways the private entities also have been addressing an overall need of human resources to run the industry. As is depicted from the previous chapters the private agencies have been involved in building a system of efficiency, timely deliverance and other technical aspects of the process. They had been paying acute attention to creating a supervisory level. The major duties of such supervisors is to take care of more skilled aspect of care giving such as planning and management of the patient care plans and also handling the aspect of explaining company rules for marketing of the service.

The duties as described in an advertisement:

- Counselling **patients**, families and their relatives by meeting them at Hospitals and Home.
- Give detailed overview about the company and its services.
- Clinical assessment of patients from Home Care perspective and understanding their medical requirements from Doctors/Discharge summary.
- Co-ordinating the discharge planning process of the **patients** along with Home Health Nurses.
- Visit patients regularly at home and assess the quality of care being delivered.
- **Patient** feedback and query resolution.
- Assist in Business Development initiatives leading to brand visibility and awareness.
- Recruitment of nursing staff for home health **care**.
- To conduct induction and training sessions for new nurses.
- Demonstrate procedures to the nursing staff in home environment.
- Daily MIS to the management on the field activity undertaken.

The second aspect that needs to be analyzed here is the benefit that is earned from the job of managing the work of the care aides. It is seen that the companies are paying an amount of 14,000 to 40,000 for skilled jobs for running home health care business. These categories of workers include positions at management levels, HR resourcing which is also for the purpose of sourcing skilled supervisory positions, finance, administration and as well as supervisory levels for the care aides. These companies often pay attention also to hiring of medical professionals to create credibility of the process. The positions of doctors and managers for operations are more significant paid more attention as they are supposed to bring more business. The lowest segment of the lather is the care workers who are not part of any such cost driven recruitment process. The other reason as can be derived from the advertising patterns of is the involvement of the consultancy agencies in the recruitment process in collaboration with the agencies.

In the privatized sector if one looks at the skills side of it, it is evident from examples that most of the other workforce is skilled highly qualified whereas the basic requirement for the placement of care aide is not based on any defined skills. The other aspect necessary to look at here in the context of private agencies is again the managerial bodies that hail from business background. The distinction is that it works distinctly only as home care and service provider unit. The need for placement thus also include hiring of Human Resource management officials for better talent acquisition specially for managerial and coordination and system management.

In this process of finding the placement patterns of for the care aides it is also important to know about recruitment of the supervisors. Again in the case of the private bodies such as Max it is turned out that the managerial level appointment happens through the HR unit of the hospital. The hospital has collaborated with a housing services company and they also play an important role in the system of appointment. As far as the hierarchy is concerned Max Hospital has a manager or a coordinator that works in collaboration with the front desk customer care division responsible for managing purchase of various care packages of the hospital. The qualifications sought for the

managerial level is indeed the background in hospital management. The manager/ supervisor narrated that one of the advantages he had while applying for the job is his background in health management.

"I worked already in different other hospitals, in RML as compounder. I graduated from college and later also worked at St Stephens hospital. This was helpful for me getting this job. I wanted to be a nurse but this job is also going fine as I am able to be in health sector and with a brand like Max. I completely believe my background of working with hospitals helped me getting this job"- Rakesh, Supervisor, Home Health Care Unit, Max Hospital

The other categories that are involved in the marketing and promotion of the care packages hold a background of hospital management and experience in health division but not to clinical aspect of health. The placement of this category also falls in the larger talent and resource management network of the hospital.

"I have worked before in the field of health management in terms of hospitals where I had similar profile, managing customer relationship. I did my studies in management and this helps me build customer relationship and provide a satisfactory service to the customers of the hospital. The home care unit falls under me in terms of marketing and reaching out to the patients and families and give them better presentation of the services." Tamden, Public Relations Max Hospital, Home Health Care Unit

1.2Foreign Based Companies

While looking into the composition of work force in the private sector companies the case study of Globe Bonitus suggest that they prefer trained individuals in care giving aspect itself. The source of recruitment used by Globe Bonitus as derived from primary data is through placements in NISD, one of the training agencies.

Globe Bonitus however is making an attempt at specialising on one kind of care giving i.e elderly care and hence they are much more focussed in their recruitment processes. The company unlike the private domestic for profit company does not showcase stronger focus on building a supportive network for better outreach or business. As states by one of the supervisors to health care aide the objective of the company is to hire specialised person for elderly care. The company wants to build its brand in assisting elderly in daily activities of living and managing well being (shared by a supervisor at Globe Bonitus). She further added that therefore they go for placements to NISD, one of the major institutes present right now for training in geriatric care.

Further the company also focuses on enhancing capacities of the health care aides through their induction training programs. Another health care aide from Globe Bonitus added that recruitment process is complete only after a month long induction program, where they orient about necessity of care givers for assisting elderly to obtain well being through physical and emotional support.

Apart from focusing in hiring very specialised health care aide as priority, the company also has paid a ttention to building a supportive system around health care aide. Thus they look for hiring supervisors with advanced degree and knowledge of managing a team of health care aides as well as maintaining relationship with families. The company has approached NISD again and recruited pass out from year long program that builds advanced knowledge (course details of NISD in annexure 5) on geriatric care (policy information, community work and counselling as core skills).

The company has a structure of where health care aides are providing direct care with supervisors above them that extends supporting hand as well build relationship with families. Finally there are mangers appointed by Globe Bonitus who are from social work education and they manage the program on behalf of the company in India. Apart from that they also have their country representative for India who visits and conducts workshops with health care aides from time to time.

1.3 Other Avenues

Private companies like Apollo, Max and also use snowballing through existing staff for recruitment at times. These contacts of previous employees play a very important role in recruitment. Companies like Max Hospital also recruits from the Max Hospital's CSR NGO. They reported recruiting approximately 30% of the health care aides from the hospital's CSR unit.

2. Private not For profit

As opposed to privatized network of care giving agencies, the philanthropic organizations and the NGOs are adopting different methods of recruitment. As indicated from the web search there is not much evidence of this type of institute recruiting through such portals. These institutes rather work in a charitable mode and adopt model combining clinical practitioners, social workers, nurses volunteers and family members. As reflected from the information on website the other jobs such as marketing and promoting this kind of palliative care is not given planned attention. The model is service oriented and the generally it can be deduced that it works on the premises of team building for palliative care methods as indicated on most of the palliative care literature. The NGOs or the philanthropic organizations that have been registered as societies (Societies registration act, 1863) or trust act as trusts also distances itself from a commercialized model and focuses on the part of nurses and doctors and social workers. The model as it seems however lacks the presence of health care aides as a separate entity and most of the tasks is carried out by the clinical bodies which often are disdained by them. There are only a few organizations that have paid attention to building specifically care givers for long term home based care.

As far as the philanthropist organization is concerned Can Kids have not paid number attention health any to hiring large of care aides (http://www.cansupport.org/new/about-cansupport/careers). Based on observation and informal conversation the researcher found out that the agency has a s system of working in teams comprising of nurse and health care aide. These health care aides help patients living in the Can Kids' care home in daily activities of living as well as assistive care. They work in conjunction with the nursing staff. The not for profit company has hired a nursing head who takes care of clinical matters of the patients and supervises other nurses about needs of the patients who in turn seek support of the health care aide for assistance to patients to lean, sit on bed, bathing etc.

These health care aides are nevertheless considered to be low skilled and lowest in order. Often the nurses have conflicts with the health care aides. There seems to be a general absence of respect for the work of health care aide among nurses. The recruitment process for the health care aides here are mostly through word of mouth. The present health care aide reported that she received information about the job while she was working at Max health care through a friend in Can Support who was aware of the vacancy. The agency informed that they publish advertisement on news papers but mostly verbal information helps recruiting health care aides. Moreover they at times only have relied on verbal communication as they do not want to incur more cost for recruitment for one single health care ai de appointed for each centre. The other not for pofit such as Can Support provides home based care as well and requires health care aide for home. They generally conduct interviews for health care aides after posting advertisement on their websites (http://www.cansupport.org/new/about-cansupport/careers/). The health care aide here as well works as part of palliative care team consisting of nurse, counsellor and doctor. The health care aides interviewed did not report any dominance of clinical staff on them as they believe the work to be very intimate in nature and thus requires specific skills. They shared not talking openly about hierarchy within the team they do feel at times that the others consider the position of the health care aides to be lowest in the ladder.

3. Training Institute

The case study of NISD (Annexure 15) indicates that there is a presence of somewhat a public private partnership in the placement systems of these organizations. The officials stated that in recent times collaborations have grown with privately owned companies and hospitals. Globe Bonitus is one of such companies that have approached NISD for conducting placements with them. The officials believe that this is the most efficient way to enhance the

demand for the work and promoting the cause of better geriatric care. The institute also has recently been trying to reach out to private hospitals and established connection with Max hospital. It turns out that one of the major motives of the institute has also been to ensure complete placements of the care givers they train.

"As we provide training to the care aides the focus always also has been on enabling more and more of them find placements in the care industry. We see that the need is more in a group who can provide enough prices for the services. Hence we find it alright to collaborate with private bodies. There are so many other programs in health that they are doing well collaborating with private bodies. This way atleast we are fulfilling the need of generating more employment as well as more attention to geriatric care. The Globe Bonitus is one of the first companies that came to us and I think that collaborations have worked well in terms of placing the care givers. There are other avenues as well. Many of our care givers are also placed with NGOs and old age homes. We and our directors think it is important to explore all the avenues and the private sector is growing so surely it is inevitable to be part of this program" - Doctor Aninidita, Trainer at **NISD**

As indicated by the examples of the private bodies, the case study of a company which is invested by foreign company indicates that for placement of care aides generally the sources had remained snow balling or direct placement from the training organizations. In this case for elderly care the governmental program of NISD remains a common source for both Max Hospital and Globe Bonitus. However for the other cadre of workers they often have opted for websites or job consultancy portals. In case of Max Hospital the decision of hiring for higher level posts, the hospital authority sets panel. For the purpose of hiring care aides this generally is taken care by the supervisors or the management bodies.

"The hospital does not invest a lot in hiring of care aides. It is mostly done through existing networks

and collaborations with training bodies. We generally circulate it amongst our own employees who informs, seldom have we used newspapers or websites. This category of workers is neither technically advanced nor is they very much educated so there is no point of disseminating information like that. Moreover we have now collaborated with NISD and with an NGO managed by Max itself who provides us with workers."- Rakesh, Supervisor, Home Health Care Unit, Max Hospital

As far as the hierarchal structure is concerned the placing of the care aides are the lowest and they are mostly responsible for execution of tasks rather than planning. Although the websites of the hospitals often state of personal home care plan for the customers, the involvement of the care aides in such plan are not visible.

St Stephens Society has used existing staff as they planned to extend their service. Apart from that as it was a community based intervention, hence they opted for members from a women's group itself. However there is one common aspect with the public training program, inclusion of a person from clinical background for teaching the basic and clinical aspects of care giving. The initiative focuses on the community of Sundar Nagari they conduct community meetings and motivates women to work as health care aides. The health care aides generally do not face any issues of hierarchy or discriminations, reported by them, because they belong to one self help group.

4. Placement Cells

The next type of institute is placement cells and they also often have posted their advertisements to look for professionals who can manage their human resources, management and accounts (https://www.naukri.com/healthcare-recruiters). Following a similar pattern along with other care giving agencies they are recruiting through common job portals on internet. As is being depicted a lot of emphasis has been put in the area of customer care in the recruitment process for the purpose that the services needs to be competitive with others. The interesting fact that can be noticed in the advertisement is how the emphasis has been laid on the cadre of managers, sales and marketing

personnel, trainers had been portrayed as highly efficient with promising better customer satisfaction. The following image of page recruitment can depict how the placement cells as well have taken note of the fact that there is a need of placing managerial position for hiring through online portals. The categories that are highly demanded for such placements are the HR personal, customer managers. The essential skills looked for in the job entitlements are majorly communication skills and ability to speak to market. These jobs demand better presentation skills which are definitely a necessity for attracting more clients or collaborations with other stakeholders. The online job descriptions also come with demands for trainers or supervisors for such placement cell companies that come with the required skill sets of good spoken English or soft skills. It has been found during field studies that the need of having soft skills training for care givers is essential to this business. This comes as a selling point for the placement consultancy services. Amongst the category of care givers who are actually responsible for execution of the tasks the clinical nurses are the ones that get its place in the advertisements... The care givers associated with home care in terms of executing additional activities of daily living are not recruited much from the online portals. It is reflected and later analyzed in the section below about case studies that most of these care giving networks find it much more benefiting to invest more energy and money on recruiting of managerial and planning personals rather than on actual care givers. Moreover as largely this category is less educated and are not versed with virtual world the methods of recruitment are more organic in nature. The type of advertisements posted online by the placement agencies for range of home care worker recruitment including health care aide. These are posted websites like www.narkri.com, www.indeedjobs.com that is focused on talent sourcing for variety of jobs. The companies also generally use the portals for recruitment purposes. These portals are often used for mostly recruiting the managerial level of workforce (annexure)

5.Self Employed Health Care Aides

The category of self employed health care aides actually do not associate themselves with any particular agency, however over the time they have built a network of hospitals and placement cells who keep providing them work.

The interviews conducted with self employed health care aides shows the struggle of this group to find regular employment. As far as background is concerned the self employed category of workers has ranged from uneducated domestic maid to educated BSC nurses. Hospitals such as Mulchand Fortis who have not started its own company play a role of mediator often between families and the health care aides. In this case there are no set employability criteria and it mostly depends on the self employed individual's capacity to build network to gain work.

The other kind of network generally explored by self employed health care aide is family network or social network (Neetha, 2004) This is very much a common practice for domestic maids who also work as health care aides. Mostly these categories of health care aides gathered from information collected during this study find jobs based on trust, such networks and their past experiences in care work or working with families.

" I have been working as health care aide for while now. I was asked to attend a patient in one of the families and they reached out to me through a friend of mine who works as domestic maid in the locality. My task was to take care of an elderly person. I washed her clothes for almost a year, cooked food for her and also helped her to use toilet. I have neither done such work before and nor I have been trained in any ways to do that. The employer only asked if I am comfortable taking care of an elderly who is completely incapable of moving. I saw the person and met her. Despite not having any experience or training I began the work believing I Self Employed will eventually learn." Nirma, Health Care Aide, Slum RK Puram

The other category of workers in the self employed category is that of nurses. They generally state that they obtain assignments through their networks with doctors or other nurses in hospitals. In this case researcher found that MoolChand Hospital in Delhi has acted as a network for many of these nurses who are also working as health care aides. The hospital generally talks to the families of patients or any elderly patient about their need for home health care. As further reported by the health care aides from this network , the

hospital has a list of contacts and allows patients and their families to recruit the health care aides themselves. The families are given certain contacts based on geographical locations and they are instructed about the kind of services provided by such health care aide. However as far the salary is concerned they already fix it with the health care aide. The families contact the health care aide directly and hold interviews. There is portion of (10%) of the first salary received from such assignments actually goes to the person who finds this work for health care aides. One of the health care aides narrated that he has been very happy with the whole process, as there is no middle person who interviews them and he can directly contact the family which helps in creating better bonding and right expectation among families. He further adds that although many a times the numbers of assignments that come are less and it is hard to sustain financially, this method of working gives freedom.

There is also a firm belief among this category of health care aides appointed through private hospitals that they are better off than the nurses in private hospitals. They however believe at the same time that the main problem with the whole process of recruitment in the home health care industry is lack of uniformity. Truly to add to what the respondents have shared , within the self employed category of health care aides there is difference in terms of dignity and freedom felt by them. In contrast to what has been shared by the health care aides who finds work through this private networks the domestic maids, often feel less paid and not free in their work environment. The problems of irregularity of assignments also persist in case of self employed domestic maids / health care aides.

6.Job placements for NGOs

As opposed to privatized network of care giving agencies, the philanthropic organizations and the NGOs are adopting different methods of recruitment. As indicated from the web search there is not much evidence of this type of institute recruiting through such portals. These institutes rather work in a charitable mode and adopt model combining clinical practitioners, social workers, nurses volunteers and family members. As reflected from the information on website the other jobs such as marketing and promoting this

kind of palliative care is not given planned attention. The model is service oriented and the generally it can be deduced that it works on the premises of team building for palliative care methods as indicated on most of the palliative care literature. The NGOs or the philanthropic organizations that have been registered as societies (Societies registration act, 1861) or trust act as trusts also distances itself from a commercialized model and focuses on the part of nurses and doctors and social workers. The model as it seems however lacks the presence of care giver as a separate entity and most of the tasks is carried out by the clinical bodies which often are disdained by them. These NGOs look at home health care as holistic aspect and they often have hired home health care teams. To cite an example here, the researcher derived from the field based analysis of the Can Support that they hold a space for the terminally ill cancer patients and for those who are completely on the verge of death is asked to live with families. In this case they believe that support to families is required and hence they provide a home health care team comprising of doctors, nurses and home health care aide. Here the main task of home health care aide is to ease out pain management for the patients by providing him or her assistance in daily living.

> "We believe it is important for the family to have a whole some experience and a collective support system. The goal of palliative care is to provide that kind of assistance to families, thus home health care aide do not work in isolation when it comes to taking care of patients at home. We work under the nurses and follow their instruction to work with patients. It is important for us as often there are clinical conditions of patients which create many restrictions for patients as far as daily life is concerned and being their guide in daily life we must be aware of everything. We never intervene in any work of the nurses or doctors but feel it necessary to tell them about any new development of patients. We often have meetings with others in home health care team to discuss progress of patients as well"- Namita, Home Health Care Aide, Can Support,

The other kind of Not for Profit networks that exist in the home health care industry often do not have home health care services ,but they tie up with many other voluntary organisations for providing such support to their patients. This outsourcing of home health care also has worked as another way of hiring health care aides. In this case there are organisations such V Care supports hospice care centers such as Shanti Avedana in their care work (www.shantiavedanasadan.org). This voluntary organisation emphasises on skills of counselling apart from knowledge of assisting patients for activities of daily living. They believe that it is important for the health care aides to be a counsellor as well as the patients often face massive breakdown because of their situations

Conclusion:

To conclude it can be stated that the placement patterns in private sector is very much tilted towards the profit motive of the organisations. They thus pay immense attention to hiring of managerial level of workforce. Nevertheless there are also certain agencies who have been trying to create a brand image of health care aide through hiring mostly trained care aides, Globe Bonitu following the path. The recruitment process for not for profit NGO are more value based. The training institutes' focus is mainly on building more and more livelihood options for its trainees and thus they focus on the part while recruiting.

Chapter 5

Socio – Economic Profile of Health Care Aide

The chapter discusses profile of the Health Care Aides interviewed during the study. This includes variables such as their sociological profile i. e caste, religion and migrant status. The other variables include demographic profile of the Health Care Aides (age, gender, marital status and the household size), economic profile i.e the income size of the family, wages of health care aides and how many of them are sole bread winners. Profile of health care aides in terms of their education and career journey, kinds of home care services provided is also analysed in the chapter across five typologies discussed in previous chapter. The study aims at understanding the connection of sociological and economic profile with caste and religion as important variables in India, as literature review indicates that most of the health care aides in western context come from races such as Hispanic, black that are socially and economically marginalised. Again migrant status of the Health care aides is also profiled here to examine the linkage of migration to care work. Second section delves into demographic component of health care aides to analyse which age group is highly involved in this work and also to look at gender to analyse if care work is feminised in nature in Indian context as well. Educational profile of the health care aides is being assessed to understand the need and requirement of the industry. It is also stated in review that families with low income or no other employment options available take such jobs, thus drawing from that link between economic hardships and care work is also analysed in the chapter.

1. Sociological Profile

Table No 8: Sociological Profile of Health Care Aides:

Sociological Characteristics	Private for profit companies Domestic	Private for profit company foreign		Training Institute	Private not for profit	Placement cell	Employed through Social Networking		Total (N=36)
Agencies	Max hospital	Globe Bonitus	NISD	St Stephens	Can Support	Verghese	Private Hospitals (Moolchdand)	Family network	
Religion									•
Hindu	3	1	2	7	1	4	2	2	22
Muslim	0	0	0	2	0			2	4
Christian	1	2	2		1	2			8
Sikh	2								2
Social Categories									
SC	1					2		3	6
ST	2		1	2		1		1	7
General	3	3	3	7	2	3	2		23
Number of Migrants									
	5	3	3	5	2	6	2	2	28

The sociological profile of the Health Care Aides is defined in the context of their caste, religious groups and migrant status. Literature in Indian context shows that there is history of lower caste being engaged in low paid and work that is socially undignified. Having stated that the home care work is defined as dirty work in literature (chapter 1) the understanding of caste is necessary in the context of India.

As far as sociological profile is concerned the majority of heath care aides are from Hindu religion (22) across five typologies, 8 belong to Christianity, 4 from Muslim religion and 2 Sikhs across all the five typologies. The religious background in overall shows Hinduism is the most prominent religion but there is also a presence from other communities.

A further analysis of religion based on typologies it is clear that the privatised network of care giving agencies which has both for profit (domestic and international) and not for profit companies have more Hindus (5 in total number) than other religion. However the foreign based company profiled showed more number of health care aides from Christian religion.

As far as religion is concerned the training institute has more Hindu health care aides (9) than Muslim (2) or Christian (2). The St Stephens Society also has presence of Muslim health care aides which is not present in other among care work agencies. One of the supervisors from the agency stated that as St Stephens Society is catering specifically to community of Sundar Nagari which has presence of both Hindu and Muslim population they reach out to both for such opportunities. However they also stated Muslim communities not being very responsive to such work over past 12 years of its functioning in the area.

The placement cell also has more presence of Hindu health care aides; 4 of them of being from Hindu religion and 2 from Christianity. The number of health care aides from Hindu religion is also high in self employed categories they have a presence of health care aides form other two religion as well.

Secondly as far as social categories are concerned caste wise major numbers of health care aides are from general (23) followed by 6 of them hailing from SC and 7 from ST background. It is again evident that most of the care aides are from general categories, however the sector wise analysis showcases that there are certain typologies within care giving agencies in which some social categories have more access than others .This differences are analysed below based on each typology.

The private agencies or networks in case of private companies both for profit and not for profit showcases more Health Care Aides from general caste (n= 8) than from SC (n=1) and ST (n=2) category. Out of these only Max hospital showcases presence of SC or ST categories in their workforce. Although the key informants have noted that there is never a discriminatory approach of the agencies in hiring the sector favouring women from general

categories in agencies having better job safety in comparison to others (placement cells, self employment) is vehemently present.

As far as social categories are concerned again majority of the health care aides who have access to these training institutes are from general categories. The number of health care aides from general category is 10, followed by 3 women from ST categories.

The placement cell has more Health Care Aides coming from SC and ST category is 2 and 1 respectively and general category is 3. The number of Health Care Aides is from SC and ST category is higher in comparison to other agencies. The placement cell agency owner also informed placement cells existing in Delhi hiring more health care aides from SC and ST categories from across the country.

The number of health care aides from general category in self employed network is lowest in number which is 2 and higher for SC and ST category. This implies better access of trained and regularised network for higher caste group.

Majority of the health care aides are migrant. Most of them have moved to the city with their families and later out of many job opportunities they searched opted for care work as one of them.

Secondly as far as migration is concerned it is visible that most of the health care aides are migrants (n=28). Out of this total number placement cell has slightly higher number of health care aides who have a migrant status. A health care aide from placement cell stated that a number of such agencies travel to various states specifically to eastern side to recruit for care giving or domestic work.

Similarly both private for profit and not for profit Max and St Stephens have migrant workers, however unlike the placement cells these heath care aides have not migrated only to avail care giving work.

1.1 Sociological Background of the Key Informants

In the privatized industry the groups involved directly with provisioning of care the supervisors' category has been occupied by a number of highly educated well to do family members. The hierarchy remains as in case of Max Hospital the in charge for the entire customer care that also manages contact with the entire unit of care givers. It is indeed significant that these sections of staff who manage the cost of this services or takes strategic decisions.

The supervisory staffs at the hospital are mostly from general caste (85%) and have high educational background. Indeed as one of the staff members at lower level handling execution shared the following

"I work as a supervisor here and I also have worked in many hospitals supervising institutional care work. Later I got a job with Shine and Standard Company and now I manage the execution of home care business and also housekeeping here in Max. There are lot of departments associated and the home care department in Max is mostly taken care by the people who takes care of marketing and management of business is taken care of by the customer care department and front desk. In fact the care plans are created by the doctors without much involvement of care workers. One can say that the category of care aides and in this even the supervisors like us decide on which care giver would go to which families, distribution of their pay rather than any other strategic decisions. In fact I feel this is one of the lowest positions in the hospital as there are special days celebrated for every cadre of workers but not the care aides. They are the lowest category of workforce."- Rakesh. Home Health Care Aide, Supervisor, Home Health Care unit Max Hospital

Although it seems that in case of private hospitals the doctors and marketing department taking more control of designing the planning program, there is a slight difference in the profile of the supervisors and their position in the program. As reported these agencies are also commercialized in nature but they generally include the section of supervisors in planning for palliative

care. Most of the supervisors are from the general categories and hold previous experiences of nursing or working in clinical sectors. The other category of trainer is that of care aides' supervisors who in the foreign agencies mostly are trained by professionals of the company itself who often hold the experiences of nursing as well as being part of philanthropic nature of care work

2. Demographic Profile

Table No9:Demographic Profile of Health Care Aides

Typology	Private for profit Domestic	Private for profit Foreign		Training Institute	Private not for profit	Placement Cell		Self Employed through networks	Total (N=36)
	Max hospital	Globe Bonitus	NISD	St Stephens	Can Support	Varghese placement agency,	Private Hospitals (Moolchdand)	Family network	
Gender		1							•
Male	1	1				1	1		4
Female	5	2	4	9	2	5	1	4	32
Age (Years)									
Less than 25	2		2			4	1		9
25-35	3		2	3	1		1	3	13
Above 35	1	3		6	1	2		1	14
Marital Status									
Married	5	2	4	9	1	4	1	3	29
Unmarried	1	1	0	0	1	2	1	1	7
Household Size (in Number)									
Four or less	4	2	1	4	2	2	2	1	18
Above Four	2	1	3	5		4	0	3	18

The table on demographic profile includes variable such as gender, marital status and household size of the health care aides. As literature indicates that there is a presence of more female health care aides than male examining this variable is crucial across five typologies as well as to self employed health

care aides. The data reflects that there is a presence of more female (n=32) than male health care aides (n=4).

In private network of agencies both for profit and not for profit sector shows presence of more female health care aides (n=9) than male. Indeed the supervisor at Max Hospital states that there is around 300 female care givers appointed so far and only about 5% were male. As shared by the key informants it often becomes difficult for male candidates to manage their family with such low wages and most importantly irregular mode of care work. He shared that the demands for male care giver has always been there and he believes more so than the work being genderised in nature it is the status in the society and the income that prevents men to be part of such work.

"It is hard for men to be in care giving work for long term. Firstly the job has very low respect and secondly there is not much scope always to be promoted. If a man would want to have a long term career then this job is not right. Moreover there is not much salary for men for such work. Thus the motivation for men to join such cleaning and being that personal with patients and family is not present in this area of work. The other reason for men not being able to be part of this is the irregular nature of this work. Till now Health Care Industry is trying to get more and more business, as in nascent stage, it does not always get enough employment opportunities. But I think the main reason is that it is not considered as a man's work" Rakesh, Supervisor, Max Hospital Home Health Care Unit

This was corroborated with many other across the care giving agencies. The key informant at Home Health Care agency, Globe Bonitus, share that mostly women are drawn into such work. The supervisors at the agency further add that there has never been any deliberate attempt in creating it a kind of work oriented towards women. It is surely a task where both men and women are required, but as the kind of work is mostly carried out by women in families ,hence there is hesitation among men to join this kind of work. This surely is believed to be a work derogatory in nature for men. Globe Bonitus, yet has few male health care aides appointed by them who are not in sync with the

belief that the nature of this work is feminine. The supervisors also added that the job profile of the health care aides especially for geriatric care is much specialised in nature and both men and women equally can obtain the skills required for it. She further added that there is surely a need of breaking this stereotypical nature of care giving being just a woman's work.

In case of training institutes as well the number of women health care aides are more in number than male health care aides. In this case the researcher indeed could not find any male health care aide available with the care giving agency. The key informants at St Stephens Society stated that although initially they wanted this work to be female centric they tried training men from the community as there was a demand for male care aides as well among families, however this could not happen as many men refused to do such work because of the belief that it is feminine and derogatory in nature and also have no scope for growth.

"Our main aim is surely to empower women of the community and contribute to society at the same time. Thus we made a combination of care giving and employment which could benefit the society as well and we also fulfil our goal of providing more livelihood options for women in need. However we later as families with male patients also put forth demands of male care givers and many a times some of our female care givers felt really uncomfortable dealing with male patients, we thought of training male care givers as well. But the idea did not take off and we could not find men who are interested in this work. This was termed as Janani wala Kaam; work of a women. Even the fact that it was paying better than the daily wage work, it did not make much difference. We believe it is completely about dignity and respect for men and hence they do not join this work"- Doctor Anita, Trainer, Home Health Care unit, St Stephens Hospital

However the minimal number of male health care aides that exists in Max (n=1), Globe Bonitus(n=1) Verghese placement cell (n=1) have reported nothing feminine in this type of work. They further argued that the need for men as care givers is essential for male patients but the concept of women being better

carer overpowers that need. Mohan (name changed) one of the care giver with Globe Bonitus.

"I think there is nothing feminine about this work. I feel fine doing this work. I have worked before in NGOs and lot of other places. And I find this work interesting and fulfilment in the work I can serve someone elderly or help someone cope with end of life condition. For me there is nothing low status in this for men. Moreover I believe now more and more men would join this work as the work is really gearing up and I see lots of perspective in it more than any social sector job I was part of." Mohan, Male Health Care Aide, Globe Bonitus

Similarly there are men as well in the self employed category of work who believe in the gender neutrality of this kind of work. This has been considered as path for better career development in the field of care giving. Thus this kind of work is counted essential for gaining more experiences of caring.

Among the self employed section a male health care aide also reiterated what has been shared by the male worker in Globe Bonitus. One of the men interviewed who is professionally a nurse stated that this kind of work really helps in building new skills and add to his larger experience in nursing. He also added that this is only a social construction and a pressure on the minds of men that lead to more women in the care business. Moreover he adds that it is also a mindful strategy of the market as the society at large buys that women have better caring values the care giving service providers use it as strategy to market their product at times.

"I am fine doing this work. I worked as nurse before and I left it because of added pressure in that job. I think this experience is helping me build my career in health and well being. I have both experiences of working on the aspect of clinical and well being of patients. I think the notion of it being women oriented work would change slowly. Like before nursing was considered only as women's job and now gradually the notion has changed. In similar ways the notion in case of care work also would change with more and more recognition of it being a work, better pay and regular assignments. I also feel that the society traditionally values women as carer and the market use it to their benefit. The

need for men is there for sure but the network of providers are scared of taking more men as that might slow their business, as the need is there for men but the preference many a times are for women due to this larger idea of women being better caregiver. I also think it is a matter of payment and as women does this kind of work as part time or a temporary job to assist their husband the companies find it easier to hire them. I think the dynamics work in both ways both from the society having a misconception about women and the markets not exploring or experimenting with the idea. But I have complete belief that it would change as the industry will slowly shape up more. It is too recent now. The organised network will change its approach as it becomes more experienced. I don't work with any organised network, but I do have collaborations with hospitals and placement agencies for getting me services"- Self Employed Health Care Aide

Thus the gender gap in work is definitely present in care work, however this is more due to how women and men's work is defined in the societal context. As is depicted the fewer men in this work do not generally feel any difference or lack of dignity in such work. One of the major problem since is defining of care work in general and assessment of the market also that it is more suitable work for women due to its lack of higher payment and provisional nature of work

As far as age criteria is concerned the number of health care aides in the category of 25- 35 is highest (n=13). Within sectors however it can be analysed that the private sector in case of Max i e for profit domestic has preferred health care aide more in the age group between less than 25 (n=2) and 25-35 (n=3) in contrast to foreign based private for profit company Globe Bonitus (n=3). Max reported that one of the reasons behind them also getting health care aide who are fresher and under 25 is because they hire from their CSR unit which runs various skill program with youth in slums.

The not for profit private agency has preferred health care aides in the range of 25 to 35 and above. The training institutes however has a good number of health care aides from the age group above 35(n=8).

As per a trainer at NISD although the agency overall want to receive more number below 25 as well, the irregular nature of work which yet exists does not generally attract younger generation into the course.

The placement cell Varghese agency however has a god number of health care aides in the age group below 25 (n=4) out of total respondents. According to the placement agency there has been no definite policy on age. They hire as per the requirement of the number of health care aides and age is not a criteria. However as per one of the care aides from placement agency this is because whenever this agencies go for hiring age group from 18 to 25 actually get attracted to such jobs in those villages or remote areas.

As far as the marital status is concerned most of the health care aides are married (n=29). Again 18 health care aides have 4 or less family members as compared to 18 others with family number more than 4. In case of economic dependence the following tables will reflect how economically many of them have to support their families as well.

3. Economic profile

Table no 10: Economic profile of Health Care Aides

Typology	Private for profit Domestic	Private for profit foreign	Training Institute		Private not for profit	Placement cell	Employed through Social networks		Total (N=36)
Agencies	Max hospital	Globe Bonitus	NISD	St Stephens	Can support	Varghese placement Agency,	Private Hospitals	Family network	
Household									
Income									
(INR per Month)									
2000-5000						4		1	5
2000 3000						-		_	
5000- 12000	4	1	4	6		2	2	3	22
Above 12000	2	2	3						9
No. Of Health Care Aide as Sole Bread Earner	2	0	2	6	2	6	2	4	24

This will compose of income categories of health care aides and how many of them are sole bread winners in the family. The household income is Rs 2000 at the lower end and more than 12,000 at higher end. There are various methods of payments for health care aides across sectors (Annexure 16)

It is important to note that a majority of the health care aides are in the income group between Rs 5,000 – Rs.12,000 (22) across all the five categories and the self employed health care aides. However distinction can be seen as 5 health care aides who are with lowest income range is from placement cells and self employed category as opposed to 9 health care aides who fall in the income

category of above Rs 12000 are from private for profit companies and training institute of NISD.

A further scrutiny shows that as far as number of health care aides who are sole bread winner of the family is concerned it is lowest in private for profit and governmental training institute NISD as opposed to community based training institute St Stephens, Placement cell and self employed category. Among 24 of those who are sole bread winners in the family out 36 total respondents, for profit companies and NISD composes total 4 and others 20.

The further probe from qualitative analysis shows that economic background of such families is better off in terms of economic conditions as well. There are few such trained workers both in Max Hospital and in Globe Bonitus who are from better of families and have opted for care work as a choice out of convenience.

"I went for training program in NISD and thought it can be a good opportunity for me to develop my carrier. My family never said no to it and thought it would help me stay connected to my nursing experience and at the same time I don't have to work odd hours at the hospital. There was also a scope of being promoted to supervisory level. Although there has been never any economic pressure from my family to do an extra job but I just wanted to do it for myself. My husband works in government sector and we do not have any financial problems. However I liked the training program and believed that it can be a good way to develop my carrier further. I had a nursing degree, but it was difficult to work as a nurse because of odd hours and thus I wanted to opt something related to nursing. It surely was a career choice for me "- Binita, Health Care Aide, Globe Bonitus

The trainer of the institute also adds that the care giving as a service is neither demanded nor served by the upper middle class or the rich community. However definitely it has attained interest of the lower middle class families in urban centers as a job opportunity. Thus there is a range of care givers from households where it comes as a need for livelihood earning and most of this

belongs to lower middle class background to those who can afford to have a choice between care work and other similar paid jobs and find it a better option. The Max hospital however has added their Corporate Social Responsibility Unit and has certain portion of the staff from under privileged background. The factor which is significant is that these private networks are also out of reach for a very lower socio economic background section. One of the supervisors at Globe Bonitus added that the information of existence of such training programs or much organised network do not reach to many job seeking people from lower social categories as they have less access to sources. Similarly Max believes that is one of the reasons that they are recruiting a portion of staff from underprivileged section from their own CSR unit to create more job opportunities.

As showed in the table above and also derived from the discussion with the placement cells it comes to notice that there is an existence of lower socio economic category in the placement cells. The non- regulation of placement cells is a concern and it has been expanding its stake in the business as well. There is a strong presence of placement cells on online forum as well, although there is a high speculation regarding their registered and regulated status. As far as the social composition is concerned the source of recruitment for the placement agencies are states with tribal or scheduled caste population and migrants living in the city. Most of these health care aides also shift also from the background of domestic work to care giving work.

"The work that started doing is domestic work and I come from Assam. I came here with my sister when the placement agency recruited us. There are such placement agencies that keep coming to our village. Being from Santhal family we did not have land and also any other source of earning and my parents worked and labourers in farms. I was asked if I would be able to take care of a work in a family and I was promised some amount which now I realize is not much. However I agreed and came here. I believe the placement cells have girls from other states as well, mostly tribal girls. They are always going to all these states from where they can recruit more and more health care aides. I think there are

many such placement cells running in Delhi" – Kavita, Health Care Aide, Placement Cell Agency

The socio economic division can also be seen in the category of self-employed section. Although there is a section within this category who are freelancing and do not want to be part of any network, there is a portion of workers who are from lower socio- economic background and are ready to do care work for managing a livelihood. Most of them have migrant status again belong to scheduled caste category such as Balmiki. As the interview included few such women, one of them narrated the following

"I worked as a domestic maid and slowly I could not do go to many homes for work in one day. So I tried care work which allowed me to be with one family. There are many other women in my community who have opted for similar kind of work. We do not have any other option of earning, no land and we are from Balmiki community and not very rich. Thus we have to keep finding something that can help us making a daily living. Most of the women who are unable to manage two three families opt for such care work now. Rama (name changed, JNU old campus slum

It is starkly evident that there is a difference between the reasons for opting home health care work within these categories. Many of them whereas are just choosing this work as another career option, there are many for whom it is a mode for economic survival and sustenance. Significantly it also would be reflected in following sections that these categories of workers belonging to lower caste groups face massive challenges in obtaining right wages, better conditions of work. These categories of workers most importantly also are not able to become part of the organised sections. The accessibility to training is often not open to this category of health care aides.

4. Education and Training Profile

Table 11: Education and Training Profile of Health Care Aide

Typology	Private for profit Domestic	Private for profit Foreign	Training Institute		Private not for Profit	Placement Cell	Employed through Social Network		Total (N=36)
Agencies	Max Hospital	Globe Bonitus	NISD	St Stephens	Can support	Varghese	Private Hospital	Family Network	
Education									
No Education						2		2	4
Up to VIII				2		2			2
10 above	6	1	4	6	1				18
BSc Nursing		2			1	2	2		7
ANM training				1				2	2
Training as Health Care Aide				<u>'</u>		'			•
Trained	3	3	4	9	1	0	0	0	20
Untrained	3		_		1	6	2	4	16

Educational background of the care aides is concerned it is seen that most of them have completed 10th or have attained more education than that (total 18). A trend can be seen that total 5 of total respondents are from nursing background a unique feature of care giving industry which is also engaging a number of Health Care Aides.

Educational background of the care aides in the privatised network specifically in the context of private For Profit companies like Max Hospitals is basic as 10th pass, almost they generally preferred a health care aide who is educated and can attend to the high end income group clients of the hospital. Indeed the underprivileged section as is mentioned by authorities is included in the work force of care aides are inducted at least after secondary education.

"It is important that we hire educated people as care aides as these factors are also important for the clients and they often would want someone that can match up to their way of living. Otherwise they doubt the capability of the care aides. Although there is not so much investment or advertising through different mediums when it comes to recruitment of the care aides, it is obviously important to note that we prefer care aides who have passed secondary education and are able to easily adapt to mannerisms of such home, can speak English as well." Rakesh, Supervisor, Max Hospital, Home Health Care Unit

The training institutes like NISD also shared the similar concern and indicated that it is necessary to keep secondary education as base as the care givers in Indian context are not only taking care of daily activities but are also working as companions. They also believe that as an institution they have to keep up to a standard.

St Stephens however inducts women who have been to school and studies till VIIIth standard. They believe that the motive is not entirely profit, but also to empower less privileged women. They acknowledge the demand for smarter women who can also be companion, but they have been negotiating with their clients that it is driven by a cause. They also at the same time train the women in the center on basic values of dealing with customers.

In case of private cells the education level is not paid much attention. It seems that they provide service at much lower price and often to a category of clients who are unable to afford a high end service like other privatised network. They also believe that this decreases the demands for highly qualified care aides. Especially the placement cells also have been catering to live in care

aides, which is not the case of other stakeholders. In this scenario again the education level does not significantly play any role.

"The only assessment we make in placement cell is that the girl has basic literacy and is healthy enough to stay in the house or provide live out care work. There is no specific training program, it entirely is client driven and they only orient the care givers about their responsibilities. We generally tell something basic about the family with the care giver."- Neeti, Health Care Aide Vargehese Placement cell, Delhi

Thus it can be derived that although all the networks would want their care aides to have basic education, the level of education required is completely market driven. The educational need is not primarily linked to a uniform skill sets required for a care aide or what would be right kind of support system for the patients, but mostly what the families would demand, which is associated with variables such as affordability, social status. Therefore there is a variation in terms of basic qualification requirements for the care aides across this network. The other factor which should bring some light to how these care networks have made care work much market driven if one looks at the career profile of the workforce, training as well as background and perception of the client side

The other interesting aspect in education is the nursing background of the health care aide. There are 7 health care aides from nursing background and most of them are appointed by private for profit Globe Bonitus, Can Suppport; a non profit, placement cells. Two of them are also self employed .Moreover there is also a presence of ANMs in St Stephens training institute as well those who are self employed. One of the nurse's interviewees narrated that it is becoming common for nurses to opt for care work as there is dearth of jobs in hospitals and the health care aides still have to manage less work than nurses. Madan (a nursing professional) reported that he found about this vacancy of care giver through a friend who works in Moolchand Hospital. The hospital has connection with placement cell which places nursing aides as care givers in various localities of Delhi. As reported by Madan many of his colleagues

who are trained in nursing are working as care aides either due to unemployment or to avoid over exhausting work at hospitals.

The aspect of capacity building is very crucial when it comes to care aides specifically in the context of Industry in India which is at a very nascent stage. Here in the study health care aides receiving any form of training before joining the work has been included. In this case for profit companies like Max has started hiring trained health care aides recently. Globe Bonitu another for Profit Company initiated its work in India with trained health care aides. The training institute of NISD becomes a very good source for both these networks and formed a public private alliance. There are 16 untrained health care aides as compared to 20 untrained.

The health care aides either self employed or placed through placement cells are completely devoid of any training. The training at NISD or St Stephens can be counted as base document in the absence of any other bodies which are specialised in skills. They although teach about anatomy but most of it composes of soft skills, values necessary to deal with families and patients.

The initiative at St Stephens started as a mechanism to engage women from the community. The cooperative began with 30 women and now have employed more than 200 women over the last 12 years. As shared by the team and the members of the cooperative it was in the year 2005 St Stephens initiated this program to assist patients in their hospitals.

"We thought about a program as often attendees of patients remain clueless about the part of taking care of patient. Thus we gathered the women in the area as it could have been chance for the women also to get jobs. We spoke to them about the process of being involved in the training program and many of them showed interest"- Doctor Anita, Trainer, St Stephen Society

The program at St Stephens primarily started to generate opportunities for the women living in the community. It was initiated as a Self help Group, a cooperative for the women. Thus the initiative began as a skill building institute for women from the community along with other training programs run by St Stephen Society.

"We were supposed to work with the women in the community. The cooperative began long back and the care program for the women was added. We also have various other livelihood generating activities. This program was to empower women from the community and use their potential to serve the society. It did work well in this case scenario"-Doctor Anita, Trainer at St Stephens

As far as spreading information is concerned it is passed to the community through already existing network of women. The demand for such work also comes through already existing network and the patients admitted in St Stephens's hospital.

"We know each and every household in Sundar Nagari community and hence it is definitely easy for us to assess their needs. In the initial phase of training we used to visit each and every household and motivate women to join the training program. We focussed on women with basic literacy level at least those who have gone to school was preferred. The training takes place for three to four months and then we place the care givers in St Stephens Hospital. Initially there was resistance in the community regarding the suggested work but later when they realized it can be a good opportunity for them to earn money and take care of their household. Most of these women have husbands who are not working or are alcoholic which makes it necessary for them to work"- Ruchi, Supervisor, Home Health Care Unit, St Stephens Society

The other training institute, National Institute of Social Defence has been running two programs as far as the care giving component is concerned. It has programs both for bed side assistance also to train human resources for supervisory level.

"There are two categories of manpower that we train. The minimum qualification is graduation for the same. This section of care givers are trained to become supervisors in institutes mostly. The training level is indeed higher than the basic care givers, and the course duration is that of one year"- Dr Atula trainer, National Institute of Social Defense

The section of care giving workforce is given more than basic training which encompasses how to take up management in care homes. This aims at encouraging more research and advocacy on geriatric care and not to involve them in direct care giving process.

"We believe research in this area is highly needed so we encourage this section of students to take up studies. Their course component consists of more than merely bedside training. We believe in creating a cadre of frontline care worker who are skilled in public policy making, knows extensively about counselling and an engage in contributing meaningfully to geriatric health care"- Dr Atula, Trainer at National Institute of Social Defense

Apart from this advanced course they also provide training to groups with lower educational background on primarily bed side care giving which is certificate courses specifically designed for bed side care giving. This aims at building knowledge about human anatomy, palliative care giving, and assistance at the time of emergency.

"The care giving scenario in India especially in metropolitan cities at the moment is on the hands of outsiders. Earlier women used to take care of their relatives and especially elderly. There is a high demand for such workforce that can replace the working women. It is also solving the purpose of employment. This will help both the parties. Now, it is very unsafe as well for the elderly to be alone at home and hence they need support. Even if they have a family, the children will go to school and also there is so much crime taking place. No one can leave their job and yet somebody trusted is needed to look after elderly. Hence there is a growing need and we here are training a trustworthy unit of workforce who can provide care as it has become impossible for the family members to do so. The training given here is wholesome and it teaches the entire care aide how closely to deal with people. We believe they must know basic clinical things and thus the course structure includes information on anatomy."- Dr. Aninidita, trainer, National Institute of Social Defense

The institute trains bed side care givers through practical exposure to old age homes and communities as well. The course curriculum includes credit systems for making assignment, case studies related to elderly and how they can be taken care of at home. Although over the time the main aspects of training has extended beyond understanding care needs of the elderly and also includes skills of housekeeping to meet the demands of the clients. The organisation is focusing a lot on issues of etiquettes, English speaking and good communication for the trainees as governed by the demands. The major focus has shifted from looking at it is welfare oriented approach and has been driven by market.

"The orientation is more towards building human resources and it is more in terms of also giving employment to many. This is growing as an industry and we believe we should contribute towards it as it is serving both the sides of demand and supply, reducing care gap and helping people to get employed. We are in fact coordinating now with manv partners increase more private to employability of this trainees and the employability can only be enhanced by training them to be well spoken and well behaved. There is a high demand for good etiquettes and those who can speak English well look decent. They are much preferred for the job. The clients are mostly from well of background and they would want care aides who can gel with the environment of their house"- Dr Anindita, Trainer, National Institute of Social Defense

Thus the care aide training program is now very much focused on social skills of the care givers. The training program also pays attention to issue such as maintaining patience, politeness while dealing with patients. As shared by the trainers at the institute the need amongst the population is also finding companionship and thus building social skills of the care aides is now an essential component of the training.

"In second level we put disease management, oral medicine and most importantly we teach them some soft skills. The additional values we teach them is to be polite and hold patience while dealing with the clients. As the major need is that of companionship and mostly the demands come from middle and upper class families and hence they look for someone smart enough to be adapted to the life style of the person who is in need of care. Therefore the

trainees also go through skills of maintaining etiquettes. Most of the clients that come through us would want care workers who can speak in English and can read newspapers to them and talk to them when they need people .More than anything they need someone who can be there with them when they are all alone"- Dr Atula Trainer, National Institute of Social Defence

The training period however also indulges the trainees to take up assignments on elderly care and conduct field visits in different communities. The course is often followed by few months of internship at institution base care giving at Ram Manohar Lohia Hospital or at AIIMS. The work assigned to the care giver is bedside companionship in such hospitals. Although in beginning the whole process tended to bridge care gap families of both lower and higher economic backgrounds and thus involved the students in assessing the needs of elderly across all communities but at the moment the training given and the placement process is much focused on high paying category of clients.

In this section the care aides interviewed from placement cells or selfappointed care aides again have not received any formal training or training based on any curriculum. They are self made care aides who are engaged in bed side care giving as in when a need has risen and they are approached for the work. The categories can again be divided into two; who are not regular as care giver and has taken it as a temporary occupation and the others who are engaged in care giving more regularly. The former section keep on shuffling between the work of care giver and to other similar occupation and the latter has been involved mostly only in care work(this section can be found amongst domestic maids who have had long term experiences in care giving). There is difficulty in categorising "other work" as it can range from domestic maid, housekeeping staff at hospitals and other places, nurses. As reflected from data approximately 60% of this category of workers have been engaged in care work as in when there has been a need in their life for monetary purposes and a 40% of them in an attempt of entering in to job that pave the path for better life opportunities.

The housemaid and majority of the nurses have taken it as temporary step in their career path. For domestic maid it mostly comes as part of their job.

> "I was working as a domestic maid in many houses, cleaning utensils and doing other household chores. Going to different houses in the same day had become very difficult as I am old now. I was asked by a family near Malviya Nagar if I would like to take care of their family. Another woman working in that area had informed me about this. They wanted her first but she already was engaged in too many things. She asked me if I was interested and then I joined the work. I was supposed to take care of an older woman in the house. I worked there for around 7 - 8 months till the day the woman died. I was supposed to be there for the whole day and work for long hours but it was better for me than working in many places. In fact the salary was also not that bad. I left that work after she died and did not work for about 8 months until I got an offer from a professor in JNU to take care of her mother in law. I left that job just few months back as the lady died."- Savitri, a domestic maid, RK Puram, Delhi

Apart from Savitri there are many other care aides who have been temporarily engaged in care work. Nitu, a woman working as a housekeeping staff at Max Hospital with Shine and standard company (the company that is part of recruitment and management of staff associated with home care and institutional care) shared that she had been looking for an opportunity to work as care giver either in home care or at the institution itself.

"I have worked in past as a care giver in many homes through a placement agency. I know how to take care of patients. I wanted to apply for that same job; however I was late in submitting the documents. I did not get to know about the last date. However I also had experience of working in housekeeping in other hospitals, so I am doing that right now. But I am trying for the care giving job; the salary is at least higher than what I get as a housekeeping staff"-Nitu, Max House Keeping staff

5. Work Profile

Table no 12: Work Profile of Health Care Aide

Typology	Private for profit Domestic	Private for profit foreign	Training Institute		Private not for nrofit	Placement cell		Employed through Social Network	Total (N=36)
Agencies	Max hospital	Globe Bonitus	NISD	St Stephens	Can Support	Varghese	Private hospital	(Moolchdand) Family network	
Types of Care Work				I	1				1
Child care									
Elderly Care		3	4						7
Palliative Care					1				1
Care for injury									
Post hospitalisation	4								4
Multiple Kind of Care Work	2			9	1	6	2	4	24
Work Experience(in Years)							1		
Less than one Year	1	3	3	3	0	2	2	1	15
2 to 5	4	0	1	6	1	4		2	18
Above 5	1				1			1	3
Work Duration Per		<u> </u>		<u>I</u>	1	<u>I</u>	1	1	1
Assignment									
Two months or Less	2	2	2	5	1	4	2	4	22
Three months to One Year	4	1	4	6	2	2	1	2	22

As far as work profile is concerned it is evident that there is very less specialisation for the health care aides. As reflected in the table above only Globe Bonitus and NISD specialises on elderly care. Among other networks providing home health care, private not for profit specialises in palliative care for cancer support. The others such as St Stephens and placement cells have no specialised nature of care work. Gradually as one can see from data Max has started building its brand in post hospitalisation care. Further it was added by one of the key informants that the hospital has started looking at post hospitalisation care which includes any support required for a while for the patients to recover from and the home environment is counted more conducive for that.

It is important to note that how range of care have been included in work profile of the care aides as mentioned in the table above (child, injury, elderly, palliative) and most of them have performed more than one which is defined by the category of multiple care work. Although there is no health care aide specialising on child care it is part of multiple care profile. The health care aides interviewed from St Stephens society and placement cell added taking care of children as well.

The placement cells and the self employed categories have been involved in multiple kinds of work as part of their career.

Another very important aspect associated with care work is less duration of an assignment. As it involves taking care of a patient during recovery, end of life it generally does not last more than three months in many cases. The number of health care aides who are able to work maximum up till one year or so have been taking care of elderly or child care in most cases. It is noteworthy that that private for profit agencies like Globe Bonitus actually have been struggling with finding a grip in the Indian market and that is one of the major reasons for short duration of assignments. As one of the supervisors from Globe Bonitus added there are multiple incidents when they are bound to withdraw services of health care aide due to unprofessional attitude of families or very less payment offered by the families. She further added that although there is certainly a massive need and demand for home health care work the

families in India are yet not aware of tasks of health care aides. They generally lack sensitivity towards the health care aides. Thus most of the health care aides are facing challenges of coping with families. There are many health care aides who in fact has left job even in one month from joining.

This is also shared as a challenge in case of For Profit companies like Max Hospital Home Health Care Unit. Although it is further added that Max Hospital is now much better in dealing with such issues as shared by Key Informants, the health care aides shared still facing challenges in continuing work in one place.

The other issue here is that these health care aides also face challenges it patients coping with end of life situations. Many a times the assignments also get over because of death of clients. This holds true in case the self employed health care aides. Most of them report shifting from one assignment to another because of such circumstances.

"I was working with a family in JNU itself. They really liked my work. I was with the family for almost three months. I was doing fine and the family also treated me well. However I could not work for more time as the woman I was taking care of died. She was critically ill. Later I tried to find other care work as I found it better paying than regular domestic work, but I am unable to find any work till date. I am actually back to working as domestic maid again. I am still looking for this care work as I can then work for one family for full day and do not have shuffle from house to house" – Binu, Self Employed health care aide, JNU slum.

It is noteworthy that such incidents are more common for new comers like Globe Bonitus who has set up their work in India recently and also the self employed health care aides. As one of the key informants at Max Hospital stated that as the industry is still in its nascent stage, there are no binding rules and the agencies generally develop skills of negotiations gradually which helps them find more work for their health care aides.

Again for placement cells as well finding long term work has become a major problem also because there are lot of regulatory issues in this kind of work. The placement cells also do not share the exact job profile of the health care aides which makes it extremely open ended for the families. This results in lots of drifts between families and the health care aides leading to abrupt end of assignments.

Conclusion

This chapter reflects the socio- economic condition of the health care aides and evidently distinction can be seen within the typologies. The organisation with better pay and working conditions is accessible mostly to general categories. Secondly although one can see there is some kind of effort made by few organisations to make care work organised there is still chaos in terms of their responsibilities and profiles as reflected from the table on care work profiles.

Chapter 6

An Analysis of Work Experiences of Being a Health Care Aide

This chapter looks into care aides account on their experiences with patient and the family; their emotional and social struggles. This delves into how they had been able to fill the care gap and their experiences of the transition into the process of care giving at someone's home for an unknown person. It also looks into what had been the expectations, negotiations with the employees and the patients, how they had perceived different situations of care giving and what had been economic implications of care work including their wages. This chapter shall enquire into how the care aides have been reconciling this new contractual mode of care giving and also where do they fit into the family and socials systems of the patient. It draws comparison between paid and unpaid care giving through the accounts of informal care aide. There will be focus on struggle of paid care givers in balancing emotional burden felt at the work place and at their families as most of them are women and play the same role in both the situations.

1. The Nature and Extent of Care Situations

The initial discussion here will be on experiences of the care aides in different care situations across various networks of care providers. The section will firstly look into the work profile of care aides in private sector, one of the largest and most active in the field followed by what has been the economic situation for these sections of care aides and the regulations involved in the same.

It is extremely significant to understand the job profile of the health care aides as is defined by the agencies and also as is being demanded by those who seek their service. The job profiles often narrated by the care aides are as follows (terminally ill or elderly suffering from terminal ailment)

- 1. Arranging for breakfast of the patient (optional)
- 2. Wiping or bathing of the patient

- 3. Taking care of medicine timings
- 4. Giving clean clothes to patient
- 5. Changing of diapers
- 6. Taking the patient to toilet

Although the above mentioned duties had been shared as the overall responsibility of the care aides in general appointed for care work (NGO, placement cell, hospitals, private hospitals). However as suggested there is a care giving plan designed in private hospitals for the care givers to follow. The case is similar when it comes to privately owned companies such as Globe Bonitus who focus on creating private and customized plans for patients and hence there would be variation in work responsibilities of the care aides.

However the NGOs and the placement cell interviewed confirmed not creating any customized plans for the customers. Although the basic nature of work is same the kind of functioning is different across the networks, the job orientation and induction process is also different from each other in technical aspects. There is also a difference in how each system responds to the struggle of the care aides in carrying out tasks. As it comes as a labour of emotion one of the uniform factors across all the stakeholders is the extra amount of hours put by the care aides in the work. This becomes inevitable for many of them as they are not able to disconnect with the client at the end of the day. The care aides feel immense responsibility of taking care of patients and if not able to do so it brings a psychological guilt feeling of not fulfilling a duty as a good human being. This struggle is constant in case of almost every care giver from all networks. Almost everyone of them had shared narratives how they had kept doing extensive number of duties for the patient as they felt guilty.

"It becomes difficult to leave the patient at the end of the day. They need us for something or the other. For me it has been very difficult as I create a bond with the patient and it often becomes difficult to leave the patient. I was working for a old man in Defense colony and his daughter left me in charge. I have stayed for extra hours on may days as some need keep coming up and it is very difficult to leave

a patient who is so dependent on you. Even in last 8 years of my experience as care aide I have never been able to detach from a client. It makes me feel guilty." Neetu, Health Care Aide, Max Hospital

There seem to be also not much support system created for this extra burden felt by the care aides within the networks. Thus despite the service providers promoting its market value the care givers who execute the tasks are often unable to negotiate right working hours. The supervisors in Globe Bonitus and Max Hospital (Home Health Care Unit) stated that they have been informed about the extra hours of work; however they shared not trying to resolve the issue through counselling of the customers or creating a support group for the care aides. The supervisor at Globe Bonitus stated that one of the reasons for attrition is this extra burden of work and inability of the care aides to manage this kind of pressure. She further stated that it is difficult for the company to address the issue as it has recently been established and it does not want to necessary risk of losing a client base because of such reasons.

"Many of the care aides go through this issue of not knowing how to end the day and when to stop working for the client. It is almost there on their minds all the time and that makes it difficult for them to work as care aide for long. This problem was brought up also to the managerial persons who visit from Sweden. There were efforts to negotiate with clients but then as the whole idea is very recent, they also are not aware of what to expect from a care giver. It is hard to negotiate with clients as they then cut off service. Although many of the clients have been dropped by the company itself it has caused loss to the company. So we are also contemplating on how to deal with this problem without a decline in the market. Meanwhile we as supervisors at times try to give emotional support informally. There has been no specific training or support group system formlly created. I hope the authority would include in their next module and once the number of clients is more and the market for Globe Bonitus is steady." Neera, supervisor (name changed), Globe Bonitus

While in case of the private network the care aides at least have their job description and requirement detailed and shared with the clients, despite of which there has been instances of overwork, the training institute and placement cells have kept it open ended with no appointment letter being provided to care aides. This provides larger scope for the families to demand longer hours of work as well more confusion in the mind of care workers about the type of work as well as limitations.

Out of the respondents interviewed from the training institute, 95% of them had responded doing more work beyond what had been told to them. They reported not getting any formal document on the job profile given by the organisation. The women care givers are often told informally and during training program about the kind of work they have to do, but there is no document citing the same is provided.

"I have worked even more than twelve hours a day. Although the basic duties say that we need to pay attention to only bathing, cleaning of the patients but our duties beyond those jobs. We are more like friends for the patient. We know more about them, their likes and dislikes than the family members. Many a times I have to stay back as the patient becomes serious or need more help in cleaning and getting up, sitting down and no one is capable of doing that kind of work. The families can't do our work.Although it seems that there would not be much to do after breakfast or bathing in the morning but the patient would keep on needing us for something or the other. My job includes everything from giving a glass of water to attending to the patient while they need support"- Daya, Health Care Aide, St Stephens Society

Similarly the care givers interviewed in hospital also shared that their duties have extended to doing more work than they have been associated with. One of the care worker appointed from an agency (a placement agency of the training unit of Ministry of Social Justice) stated the following

" I have worked for many years in the field of giving care and I have taken it as a my duty, as

sewa(service of God). I now believe possibly I was born only for this work. Wherever I have worked I have always considered the patient or the old person as my own family member and had given my hundred percent. I have taken more care of the patient than the family members. They were always close to me and they would share about their own life. Initially everybody is hesitant but as I am the one who would be with the patient they would share about life. I think more than care workers we are like their friends and thus our job becomes very important. The family members can't take care of the patient so well and at times also don't do that intentionally. We would ensure that the patient has eaten and that they had taken bath. When the patient would have bed sore or would be defecating on the bed the family members can't do the cleaning part. They don't know quite well how to do such things. I remember how the family members would keep them unattended just lying in their filth for us to clean it. I was once told by patients how she felt that I was like her daughter and how I meant to her more than her own daughter. I believe we are even more important than the doctors .Doctors are there only for few hours but we are there for more than that, cleaning the patient, bathing them and even being their company in lonely hours"- Supriya, Health Care Aide, National Institute of Social Defense

It is noted that the number of workers (around 23%) have worked in their life time with dementia patients in which the amount of work increases multi fold. One of the respondents shared

"I have been taking care of dadi (grandmother) for a while now. She has dementia and is not able to move. She forgets about where things are. She often fights with me thinking I have taken it. I fight with her at least once a day. She is alone and I have to take care of everything. Her son comes back at night. I am the one who has to make food for her and take her to bathroom and bathe her, comb her hair. The nurse comes and also she goes to the doctor but I don't go with her. Her son takes her. I take care of household work. I have to be very

attentive and can't keep her out of sight. We keep our door locked. Once or twice she had also left the house and I had to run after her. If I would have been late she would have gone out of the gates but luckily I was there only and could not go farther. She had done such things many a times. It is difficult for sure but I manage it somehow but the work needs lots of patience and I hardly get any rest as aunty needs constant attention. She and I talk when she is in her senses. But she makes it very difficult at times as sometimes she would also count me as someone she does not know and would not want to speak to me. However I can't complain as I was told when I joined the work about the condition of the patient. I am not much educated and I was not sure that the condition is so severe. I have heard about the disease for the first time in my life. I thought aunty is old so I just would have to take care of an old woman which should not be very difficult."- Bina, Health Care Aide Varghese placement agency

Often it is found that the care aides have to work for extra hours beyond their assigned duty timings as the families would want to utilise maximum of work hours of the care aides. Thus the care aides would work for more than 12 hours a day and also on extra days. Most of the care aides also work for extra time or additional work as they feel obliged and often at times find them without any support system at the workplace.

"Ever since I have been associated with this work I wake up and I run to my workplace. I am there every day for 13 hours and at times even more than that. I feel bad for the patient as most of the time they like the fact that we are around especially with elderly. Otherwise there is hardly anybody around that time. I used to work with one of the women in Lajpat Nagar. She was quite an old lady and could not walk much around. She would lie in bed the entire day and no one would come and see her. This used to make me feel bad and hence I had to stay for longer at times. Now for last two months I have been staying almost every day and my children are being

taken care of by my sister" – Bina, Health Care Aide Varghese Placement cell

The care aides often have to concentrate on long hours of work as there is hardly any contribution from the families or from the clinical side. They are the ones who are solely working for assisting the patient and in case of few (approximate 6%) the only person available in the entire house for caring. This is evident most in case of the patient is an elderly. The care for terminal illnesses is less likely to be not helped by the family members. As shared by one of the care givers

"I once had taken care of a patient who was elderly and had no one at her home. Her son was staying abroad and I would go everyday to take care of him. He had a servant with him. I used to feel really bad for him and often would stay a little late and at times I also had gone on off days"- Niru, Health Care Aide St Stephens Society

As the focus has remained mostly in the marketing and clients' experience the private network has paid very less attention to systemic support building for the care workers. Similarly also in case of NGOs the attention is patient centric or families. Although there is a concern for the aides but that is limited to livelihood generation both in case of training institutes like NISD and NGO, the units not driven by profits. These problems have also not been recognized as crucial to find concrete solution in care industry. The other issue apart from extra work of hours and performing undefined roles ,is various care situations and varying experiences with the organizations .There is lack of support for coping with such problems as well and most of the care aides are learning to find either their own mechanisms to cope with it or stepping out of the profession.

2. Role and Work in Differential Care Situations

The scenario of care giving is not very specific in Indian context. Indeed there is a lot of variation and multiple range of work carried out by the care aides. The job profiles of the health care aides are not entailed generally by the organisations while appointing the care aides in specific context. In the case of

the women employed by the private hospitals and training institute such as St Stephens society they generally get appointment letters and job description in the beginning. However the role extends from being a care aide to many others. They often end up admitting to many demands of the family and the clients and work beyond schedule.

There has been no definite ways of explaining the roles of care aides in the context of Indian market, hence the health care aides end having differential experiences with every family and every set of organisations. It also becomes very difficult for the organizations to ensure that the care aides are following the same kind of job responsibilities owing to varying demands of the families. One of the care aides explained how it became so difficult for the organization she was employed with to orient the family about her definite roles and responsibilities and the rules she needs to follow. Ruchi stated the following

"I was appointed from Globe Bonitus after I passed out from NISD. The first house I served was in Chankayapuri and I was supposed to take care of a person who got bed ridden because of an accident. It was although not for many days the number of demands increased within a few days of my appointment. The person only had his mother with him and she often wanted me to stay back. She said she might need help at night with her son. Staying at night was not part of my duty and I tried to explain it to her and she kept on asking me. I also did not feel comfortable staying back with the family. This led to problem in my workplace. I finally could not with these demands and asked my organisation. As they are a company based in Sweden they were also not aware of how to tackle these situations. They also asked me if I would change my mind, but I said I won't be able to do so and hence I withdrew from the work at last. I was lucky that the organisation listened to my problem."Ruchi, Health Care Aide, Globe Bonitus

However such unclear job profiles and the issue that the population demanding for care aides are not oriented well about their job profiles This often leads to confusion and blurring boundaries between care work and work of a domestic maid. There is much more confusion in the case of placement agencies and the care aides who are self employed. One of the self appointed health care aide who also once worked as a domestic maid explains how she did both domestic and care work. Even though she would be there for just taking care of an elderly person, she was also working for taking care of the household in the meantime in more than one occasion. Nitu shared the following

"I was asked by one of the previous employees to provide care to her ailing mother in law. I was supposed to be in their house for around 10 hours and this was primarily to on bed side of the person, to help her clean herself and also to make food for her. However as time progressed most of the times I was also asked to take care of the house. She would often to leave house for work and hence would ask me to cook food or wash extra clothes. Sometimes she also paid extra money to me for additional work" -Binu,Self Appointed Health Care Aide, Old JNU slum area

Thus the roles and responsibilities of health care aide in the context of Indian industry often get mixed with other sorts of household work. Approximately 94% of the care aides shared working beyond the limits of being a health care aide and playing the role of a companion or any other household work. There is also an issue that most of these care aides had never been also oriented well enough about their exact roles and responsibilities and where to draw a line. Also for many of the care aides it becomes emotionally burdensome to not say no when they are caring for ailing or an elderly. One of the health care aides explained how she stayed with the patient and her family many times as they were lonely and without a support system.

"I would stay back most of the times as I could say that woman was 60 years old and her husband is older than that and still they had to manage everything on their own. I felt bad that they did not have any one around them and their children were not much responsible. They would come once in a

blue moon to take care of ration and other things, but for other support the woman and the man were all alone. I therefore had stayed whenever uncle would not feel good during the day. I would be taunted by my family for doing such things. But I felt like it is one of my duties although I was never told by the agency to do such things"—Daya, Health Care Aide, St Stephens Society

The excessive non clarity of roles and responsibilities is also a concern amongst the care aides from the placement agencies. As stated by many of the care aides from placement agencies the major issue is with the family and how they portray the work of a care aide. There is no clear idea of the job profiles in the minds of the families and they often assign them with multiple numbers of duties. This extends beyond just caring for the patient and carrying out the bedside responsibilities.

Apart from this indeed many other self employed care aides shared how the families opting for care services are never accepting the professional aspect of care aides. Neither the organizations involved are taking much action towards creating that kind of an image for the care aides. One of the health care aides who is also a nurse shared the following

"I have realised how they (the families) would not understand that a care aide is supposed to only take care of the patient and nothing else. However they would still want the care aides do other kind of work. For me it has been different as they know that my background is in nursing they would ask me to other clinical work, but I know that is not how one should demand. I am still fine working here as it is less work for me as compared to hospital but the point is the concept of care aide is not that very much understood in Indian context. Indeed even the hospitals do not provide any information about our job responsibilities and limitations. They mostly go by demands of the family and whatever is required by the families"- Madan, Self employed Health Care Aide

3.Health Care Aide's Perception and Views on Coping with Care Situations

As the care giving work extends beyond the limits of simply taking care of patients, often the care aides face multiple challenges of coping with the duties. Mostly the care aides are women and it becomes difficult for them to cope with the challenges of running their household and also to tackle the problems faced at the workplace. The care situations can be intense emotionally and physically overpowering for the care aides. Moreover as care giving is often varying in nature it creates problem for the care aides to do a transition from one type of care giving to another. One of the care aides explained how it was difficult for her to manage two households continually for an elderly and a woman who needed assistance post surgery. She explained how it became difficult for her to manage the transition in both the families. Although the nature of work was similar but the types of the families were different as well as the behaviour of the patient. She narrated the following

" Coping with the entire situation for care giving is very difficult, the first few days as a care aide were very hard for me as I was treated almost as a maid which is with disrespect by the family. However the biggest difficulty arises when you have to shift from one type of care to another. People generally believe bedside care giving is simple and do not require any expertise. Unlike that it can be very different from patient to patient. I generally take break between two types of work, however once or twice I have worked at two houses continuously. In one of the houses I was supposed to take care of one of the patient post surgery and the other one was an elderly. It was very difficult to do the transition as the kind of care needed by the patient who just had surgery was different from the elderly. I had to be very careful with the patient with surgery, in terms of how to turn her and other kind of things. Apart from the difference in skill sets there was also a difference in the ways the families behaved with me. They were nice but there were limitations in one of the households in terms of what kind of bed sheets to be used and so many things about using the

bathroom properly. They would always have a complaint about me on how I have left the kitchen after I have made food for the patient. The member of the other house were very flexible, however I also would do some extra work there as the wife had surgery and the children at times would need help in taking out food etc. When I did this transition from one house to another it became very difficult for me. In both the houses I had to pay attention to nagging of the patient. The patient with surgery would be so upset about the fact that she would have to be there in bed for a long time, and her children would not listen to her. Similarly the older person would keep complaining how his children have left him just like that. After handling those two cases almost back to back I had to take leave for few days. As it was too much of an emotional burden for me" Geeta, Health Care Aide, St Stephens society

Apart from this the health care aides also often have to face situations of violence and sexual advances at times. Few of the health care aides shared how at times the men in the family would try to make an advance or would want to know more personal things about the care aides. She also added how it becomes a challenge for the health care aides to take care of a male person. She narrates how care work can be very uncomfortable for women despite the idea that it is one of the easiest and low skilled jobs

"I remember how one of my friends appointed from a private hospital (for profit private companies) was approached by one of the family members. He tried to make sexual advance on her, although she reported it to our manager and he immediately changed the placement, it happens quite often according to me, although no one wants to speak about the same. We are mostly women in care work and we many a times have to take care of male patients. This creates very uncomfortable situations as well. If something happens then there is hardly any grievance redressal mechanism. She was lucky that the manager agreed to listen to her but I know in so many cases there is no one to take care of these issues."- Heena, Health Care Aide, Can Support

4. Experiences of Family Care Givers and Health Care Aides

The information on home care also needs to incorporate the section of informal care givers. It is noted that the mostly the informal care givers are female family members of the household. It is important to note however that the category of informal care givers is primarily those who are not involved in any other economic activity. 20% of families of informal care giver also have involved paid care givers at times and have shifted to family member due to distrust or other reasons.

"I have been attending my mother in law for a long time. I had left my job long back when I had to take care of my children. My mother in law got paralysed five months back and I am engaged in her care. It does not create much problem during day time when everybody goes out for work. However it does come in between of my daily schedule after everyone comes back towards evening. I like spending time with my mother in law and I used to do the same before she fell sick as well. But yes I have other responsibilities also that is a concern. We tried keeping a paid care worker but we did not like her as she was not taking good care. At times she would forget to give food and I had to remind her."- Reena ,East Delhi, Family Care Giver

The care giving families thus often fall back on the person who is least productive economically. It is also noted that approximately 53% of the care aides are also those who themselves are elderly. Mostly the wife who also is in elderly stage takes care of the husband. There are only 2 % of male care givers who have assisted women in care giving and are not necessarily involved in direct and complete care giving.

"I got retired from my job long back and have been involved in care giving of my daughter's mother in law. She is around 90 years old and is weak. Both of them go for work and hence can't be available for care work. However they do help me when they come back from office. My son in law also helps at times while making food for her if my daughter gets late or behenji(my daughter's mother in law) is not

able to get up from the bed"- kavita, Family Care Giver (East Delhi)

5. Motivation of Family Care Givers

The issue of motivation for the family care givers is crucial. Majority of the time the care aides are women. However as far as motivation of entering into care work is concerned it is more of a compulsion and obligation for the informal care aides. Few of the informal care aides have been doing it as a favour to their relatives as well. One of the care aides shared following.

"The role I was given was because I am her daughter in law and I only have been a house wife in last few years. I have children and husband, however now I don't have to be involved in my children's work much as they have grown up. I now have this work to do. Taking care of my mother in law has come to me as a responsibility. My husband helps at times. But mostly it is me struggling with taking care of the family and her. She has been bedridden for two years now. She is not able to walk properly. My husband does not like the idea of hiring a care aide. Sometimes our maid helps us, but only occasionally. Most of the responsibilities are on me. I have never complained. I have raised my children so I know about how to care for someone. However this has come to me as a compulsion and not by choice as I am the daughter in law of the house" Nitu, family care giver, Vasantkunj,

Apart from this there are other instances as well in which the care aides were not close relative of the patient. In this scenario the primary motive is to surely help the relative. In one of the cases however the woman who was taking care of an elderly was also in later stage of her life. The main motive of her to provide care was to find a shelter with her daughter while taking care of her mother in law. She shared the following

"I am 65 right now and I had no company. Therefore when my daughter gave an option if I could take care of her 90 years old mother in law I accepted it. It was better than living alone"- Mrs Kaushal, family care giver East Delhi

6.The Challenges and Response of each Category of Paid Care Givers

Entering into a different household and providing care which is a personal task can be challenging for the care aides. Care work has been within the realm of household for a long time in Indian context and the sudden change has also led to issues in adjustment and most importantly entering into the role of caregiving for someone strange. However surprisingly 85% of the care aides said that only initially it was awkward but later on they could well adjust to the role of a care giver. The only problem was that of the families who many a times either were too dependent or too distrusting. One of the care aides shared her experiences in her 10 years of service and how she has become much more comfortable with her identity as care worker right now.

"I have been working as care aide for 10 years. I still remember I was given the duty to help an eldery in St Stephen hospital. I was very hesitant as the first task I has was to change diaper of the patient. I was standing there for a while thinking if I should look for other job.I did it anyways as I started telling myself it is just work and one needs to take it just as work. After that everything had become easier now.I have been in this service for so many years now I don't feel any hesitation or awkwardness. I think its all about time and practice."Renu, Health Care Aide, Max health care

The other issues that care aides' daily struggle are balancing their role in the household as care givers as well as to overcome burn out taking place in the work area.

6.1. Dual Burden of Care

One of the most important part of care work is that a huge portion is female care aides and they also have to carry out the role of care giver in their families. The burn out from care work, the heavy duty hours can lead to reluctance in the care aides to perform any duties at home. It often leads to problems in the families. It is often noted that the families of care aides are also nuclear migrant families with both the spouses earning daily living. This leads to confusion as there is no substitute for the care aide for her share of

care work. Approximately 72% of the care aides shared facing problem at the level of family owing to this nature of work. One of the care aides narrates the following

" I shifted to city with my husband as I really wanted to be away from my in laws. Soon my husband's salary started falling short for our family. I had to look for work and I finally could become a care worker. However the whole idea of caring for someone for the whole day was very tiring and I often wanted to withdarw myself from any household work after reaching home. Indeed I tried to keep my children at Angandwdi center and they did not like it. Later on I started living with one of my relatives here. However after coming back from work I did not feel like taking care of them much. Although I knew I had to, they are children and they are lovely. I often had fought with my husband as to why he cannot take care of the children, but he would always say that he does not know how to do that and that it is my duty. I think all the care aides must be feeling like me, but I believe balancing both kind of work is immensely difficult." Niru, Health Care Aide ,St Stephens Society

6.2Coping with Burn out and Emotional Engagement

The gap in care giving is in very much existence in the family specifically when it comes to elderly. There is massive amount of dependency at care aides at times owing to their nature of engagement which leads to emotional burden also for the care aides.

"I used to work for an amma and there were many people in the family but yet there would be no one who would care for the patient. The amma would lie in her bed for the entire day. Her son would also take her pension and would not ask for her. The woman would talk to me about her life and how she is ignored in the house. I would often buy things for her. I really got emotionally attached to amma. Her daughter in law would also not do anything. I wanted to say but I could not say it as I feel I should not speak in personal matters I could see how she

was ignored and yet I could not say anything. After all I was just an employee and they were paying me. Infact her nutrition was also compromised. She wanted to eat good food and I often had bought from shop and feed her. However I was asked to leave once when I actually spoke to the son about the need of paying attention to his mother. I left that place but I really got associated with that amma on emotional level"- Kalpana, Health Care Aide ,St Steephens Society

Often the care aides are not assisted by the family members leading to their over exploitation an excessive care load. Some of them also report how the nurses who would visit the patient often would not bother about the hygiene of the patient and all the dirty clothes of the patient would only be left for the care workers.

"When I landed once in a home where I was supposed to take care of a woman suffering from paralysis, the first day I had to clean all her clothes. I could not enter the room as there was filth everywhere and one would not be able to enter the room. Her bed sheets were stained with her filth and she was not able to move. She did have a nurse but no one had turned the beds sheets or cleaned them. I felt bad as the family members probably had not counted me different from a maid and hence I felt disgusted. But when I looked at the helplessness of the patient and that I had to do this job for earning money I did what I could and I cleaned everything" – Neeru, Health Care Aide, Globe Bonitus

This overload of work and also the attitude towards the care givers have remained an issue of concern. As shared by Rama (a care aide in Max Hospital), she felt really bad in her first encounter with a patient she was asked to clean the patient after she used the toilet.

" I really felt bad. I was standing inside the toilet with her as no one from the family members would want to go and I was employed by them. I knew it was my duty but still the first time it was hard. I helped her sit on the toilet and asked her to call me when she is done. She called me inside and I stood

there for a second until I heard a voice saying rudely, clean it. I did clean it but what I could not forget was how she asked me to do it. It made feel bad all the more. However over the time I learnt how at times they would talk. Many a times the patients are nice and many a times they are not. Same is the case with families. However the truth remains that we are not regarded with respect which I think should not happen."- Madhu, Health Care Aide, Max Hospital.

The concept of it being a dirty work is there in the minds of the care aides; however it is only in the beginning phase of their work. More than the issue of it being a dirty work the care aides are concerned about how society perceives them and their work is undervalued.

"When I heard about what I was supposed to do I thought how I would do it. It is cleaning and bathing people and even male patients. I was scared and worried. However when I did my work with pregnant women and their babies it became easy. I started the work as it was my compulsion. But slowly I started finding it alright to serve a patient. It was a dirty work, but I believed I am a doing a service to God by doing so. Moreover I could feed my family and raise my kids. Thus the dirty part of it stopped bothering me. But what I did not like was how people would look at it and how when I would tell them what I do they would make faces. I don't like that. I don't know how this work can be different. Even the doctors have to so many dirty things while checking patients, operating them but everyone considers their job respectable and not what I do. I believe the mindset should change."-Ganga, Health Care Aide, St Stephens Society.

However it is not only the care aides but those who are managing the organisation that the need of care worker is high, the demand is high and yet the work is undervalued both in medical fraternity as well general population.

"I think care aides work as much as the nurses do. Yet they are respected lesser than them. Their place has yet not been recognised with dignity. I don't know why we can't do something to respect the work of this community. If there can be doctor's day, nurses day, we should also think of praising the work of the care assistants by celebrating their day"-Mr. Rakesh, Max Hospital

7. Future Aspiration of Health Care Aides

As far as future aspiration is concerned the care aides who are in the age group of 24 – 40 showed hope for future growth. Approximately 54% of the total care aides interviewed expresses the desires to have a better future and was helpful that the experience of being a care aide would help them to move towards that direction. Out of the self employed care aides around 20% believe that the experience as care aide can help find better job and there is a chance of moving up in the lather as supervisors. However for many of the nurses who have been working as care aides it was a stop for to earn enough money with lesser work in comparison to nursing in private hospitals. However only a 10% of the care aides from community based organisations had believed that there is any scope of further growth in care work. Only two of the care aides reported shared being promoted to a supervisory level in different programs. One of the care aides shared the following

"I am not very educated and I think there is not much scope for me. I have been working as care aide since beginning of the program and still am a care aide. I can do any other job, may be as a domestic maid or something else, but I think this work is better than those jobs. I think this is alright, but I don't see any change in future. There are other care aides who had become supervisor now, that has become possible because they are much more educated than me and also younger than me. But not many of the care aides feel that there will be ample chance of growth." Binita, Health Care Aide, St Stephens Society

Some of the care aides appointed from the NISD at various places specifically with international organisation were of the opinion that there is ample scope for such work and much more acceptance and dignity outside India. Around 30% of the total care aides belived that there can be a possibility of migration to other countries for finding better paying jobs. The care aides appointed in

the private hospitals were of a mixed opinion. 40% of the care aides believed that there is a chance of promotion to the position of supervisor and even migrating to a different country for care work. Indeed one of the coordinators in the company which runs the care work program shared that he also used to work as the care aide and then got promoted as a manager.

"I believe this work has scope, as it is growing in size, more and more networks will start for providing care. The need is going to increase, and I believe like me there is scope for every care aide to move up and work as supervisor in such companies. This is the kind of work doctor or the nurses can never manage, therefore the demand will surely be for the experienced care aides who can run these organisations providing care." Rakesh, Supervisor, Max Hospital, Home Health Care Unit

The care aides in India have been facing ample problems as there is not much acceptance and dignity for this group of workers. However as there is an immense care gap, the dependency on the care aides is huge in the families. The issue remains that the care aides, formal and informal hardly gets any support from the family or other clinical staff such as nurses. This leads to pressure and over exploitation of care aides. As the regulation mechanisms are almost non-existent although the industry is generating profits it is creating massive struggles for the care aides and making the whole process of care giving a matter of struggle.

To conclude here it can be stated that the care givers lack a support system in the work place both the families and the institutes. It is often noted that despite the fact the organisation have known about the issues they have negated the same or have sidelined it saying it is a problem of mindset towards care work and it will slowly change. The organised effort to help these health care aides cope up with the problems is missing. Thus although care work has become a paid commodity care giving as a work has hardly derived any value both monetarily and socially. As it is growing as an industry there is certainly a need of ensuring well being of the human resource i.e the executioner of care, which is thoroughly missing amidst creating brand image and market value of care.

Chapter 7

Discussion and Conclusion

1. Introduction

The present study began with a question on creation of home health industry in the context of India. The history of care shows a transition in care from unpaid to paid, in global context. This study aims at exploring the nature of that transition in the context of developing nations such as India. Home care can be defined as care provided to elderly, ailing and the children at home. As indicated in many studies it reduces expenses of institutional care (Foner 1994); having said that, there is a global care gap with a rise in number of elderly and traditional care givers, such as family members opting out of care work etc.

With a global gap of care, the home health care also has moved from family members to external persons. This study focuses on understanding this transition in India as already indicated by Nath and Ingle (2005), there is an increase in ageing population as well as increase in disease burden for terminal illnesses. The National Policy on Older Person (1995) actually reinstates the need of more man power to cater to a rising elderly population in India.

The other significant aspect apart from the definition of care is the people responsible for the same. Francesca Cancian in Tronto (2005, p8) defines care as an emotional task. The definition further adds that every human being goes through difficulties, illnesses in their life cycle and they require care to cope with daily living. The study conducted by Hammington and Miller (2005) state the need for care is unavoidable during child hood, elderly stage, injuries and end of life situations. In this context many studies suggest various people responsible for care giving, pointing at self, family and community. Self care (WSMI 2013) is defined as someone taking care of his/her own wellbeing, assisting self for medication, consumption of good food etc. Self care however, is considered a very new concept as family generally has been identified historically as the main care provider, assisting the person in need, for round the clock in a comforting environment of home. Abel (1986)

indicates that indeed 80% of the care is provided by family members at home. Further many in their studies such as Palriwala and Pillai (2008) argue that it is women in families who play the role of main care giver.

The present study here also draws attention to feminine nature of care work as suggested by evidences in literature. The researcher analyses the findings of the study on gendered nature of this work both in paid and unpaid context and how it considered an inherent nature of women. Porter (1986) argues that care giving is often considered a core responsibility of women. Sharma et al (2016) suggests that in Indian situation, women by default play the role of care giver. The gendered nature of care work is well depicted in the present study. This is shared below in the key findings discussing genderised nature of care work along with others on growth of home health care industry in India i.e the typologies of care giving agencies and health care aides, marketisation of home health care industry, socio-economic characteristics of health care aides, working conditions and issues at home health care work.

The discussion of the present study is based on a theoretical framework of feminisation of labour, health sector reforms, privatisation of care, construction of "care giving labour" in the context of economic theories and sociological understanding of care work. There is a section where the researcher analyses the public health implication of Home Health Care Industry in India followed by limitations of the study, and concluding remarks.

2. Framework for Analysis

The following section entails the theoretical framework of the analysis based on theories of feminisation of labour, care economy and health sector reform.

2.1Feminsation of Labour

This theoretical framework looks at care as labour of love and its relevance to paid care work. Nancy Folbre (2000) has defined care work as labour of love implying that care is a feminine work and performed out of love and hence it comes as a basic instinct of women. Palriwala and Pillai (2008) have noted that this feminine nature of work actually is boosting the care gap. The

women who were previously working are now earning livelihood out of homes, leaving a care gap in the family.

The present study is evaluated based on this theory on feminised nature of labour and that it is women primarily who are at the core of delivering household duties as well as care work.

The study reveals how women mostly are part of the workforces and there is a gendered notion in the designing of the care workforce. The need of men in such home health care work is indeed present and yet a majority of workforce is women. The feminine construction of labour is discussed in one of the key findings of this chapter.

2.2 Economic Construct of Care as Labour

Following from the theory on feminised nature of labour there has been various debates around care economy and how traditional economic theories perceive the same. Further the present study builds on the framework on conventional economic theories and how they define masculine labour which is discussed in a study by Marzurkiewicz (2007).

Mazurkiewicz(2007) has noted that present construction of care work is actually rooted in history, how labour economics have defined women as not part of productive economy. As informed by Folbre (1991) by 19th century the women were considered as dependents. This was an outcome of the change in economy and the analysis of neo-classical theories that women hardly could be part of economic systems with the advent of industrialisation. The whole conceptualisation of care actually intimidates the basis of classical economic theory which does not recognise the need to discuss people's welfare as indicated by Folbre (1991). Thus the one who discusses care having economic value actually proposes to follow alternative school of thoughts that links economics of care to feminist theories.

Institutionalist (Chavance, 2009), an alternative school of thought discusses care as social activity and recognises gender norms as important institution in the economics. This economic school talks about importance of socialisation

in building of economic system and how it is not a matter of an individual and also can include cultural norms.

Another belief shared by Institutionalists and Feminists is the significance of power relations and conflicts in the economy. Institutionalists have used the concept of power through multifaceted systems of status and hierarchy (Waller and Jennings 1990). Feminists use the concept of power and subordination to describe gender relations in economy. Concept of gender is seen as a system of power which brings feminist theory and institutional economics together (Jenings, Waller 1990). The system of gender seeing as power indeed brings the feminist perspective of care and institutional economics together. This theory is very important when it comes to the present study to understand care work's transition from unpaid to pay and also how it has still remained feminine in nature. The study will elaborate on the finding how care work is underpaid owing to the fact that it lacks economic value based on the understanding of neo-classical theories such as rational choice theory that counts care as not a productive process.

The other theories that are useful for the present the study are concepts such as decent work which is used to understand the working condition of health care aide. This terminology coined by ILO (www.ilo.org) implies aspiration of people for fair and productive work, security in workplace, better development of self and families. This can be correlated with the experience of health care aides on lower respect paid to health care aides and how their work has limited growth as a career, analysed in the section on working condition below. This study also elaborates how the narratives of health care aide leads towards an understanding that home health care work is considered undignified.

2.3 Sociological Understanding of Care

Additionally the study will also deal with concept of "dirty work "defined as forms of work which are seen as disgusting or disregarding. As care work often is referred to as dirty work in literature (Stacey, 2006) this concept shall be used to understand the experience of the health care aides in the context of India in the present study.

As caring is an emotional practice and have sociological connotation attached to it and at the same time it is disregarded as a lower scale work it is important to understand care in the purview of sociology and how the boundaries of class, caste, race play a role in the same. Many studies reveal how paid home health care work being economically and socially undervalued is only carried forward by a certain section of society (Stacey, 2006). In western context such care work is generally done by the migrants and Hispanic communities (Stacey, 2006). There is a huge section of literature that deliberates on migration from lower economic countries to higher income one for care work (Hoschild, 2000). These migrant workers from different race often face discrimination at their work place, owing to their social status. The present study as is located in India draws an analysis of caste and religion and if it plays any role in formation of the workforce.

2.4 Health Sector Reforms

This section looks at privatisation of health care economy and its linkage with advent and growth of home health care industry. The reforms in India with a beginning in 1990s showcase the power shift to private entities and advent of public private partnerships (Tyagi, 2000). The present study also showcases how this has impacted the growth of home health care industry which turns out to be highly privatised. The other important aspect derived in the study is the contribution of foreign based companies to home health care industry. The General Agreement on Trade and Tariff (Sykes, 2008) resulted in movement and transaction of goods and services among countries. This has enabled exchange of businesses and also low skilled labour among nations leading to liberalisation and privatisation of economies. The finding commercialisation of home health care in the study showcases its highly privatised nature and how the state also has fostered its growth as an industry.

3. Key Findings

This section looks at the major key findings of the study and links it to theoretical construct mentioned above. The discussion below brings out the nature of home health care industry in the context of India through the results derived about typologies of agencies and health care aides. It secondly looks at the regulation of the whole industry and how state is fostering presence of regulated and unregulated private bodies. Then the researcher analyses the commercial nature of the home health care in India, moving on to understanding which socio –economic categories form the home health care aide workforce, their issues at care work in terms of relations with families, employees, perception of dignity of work and wages.

3.1 Typology of Health Care Aide Workforce

As home health care industry in India is in a nascent stage, it is important to understand the nature of this industry through the typologies that have emerged. In this study the categories of the health care aide are broadly divided into five sections. The important aspect is that Indian scenario shows a change in terminologies used and how the work of these health care aides is defined in the context of other countries. In western context based on literature review the category of workers who are involved in home health care is defined as Home health Aides or health care aides. This type of workforce is defined by researchers such as Stacey (2006), as someone who take care of ADL activities of patients after discharge from hospital. They are supposed to be engaged in non-clinical activities such as bathing, dressing, and meal preparation of patients. They are expected to fulfil home care needs of patients and are very much associated with emotional and need of companionship of patients. These categories of health workers in literature are distinguished from nursing assistants who are responsible for administering of drugs as well. Having stated that health care aides or home health aides are a distinct category possessing important skills in western context the present study shows that there is a wide range of variation within the home health care giving scenarios in India. These differences can be seen in the context of terminologies used and typologies of home health care aides.

The terminology in India is varied and depicts informal nature of the industry. The types of names that are used across the agencies providing home health care show similarities but there is no absolute uniformity.

The major terminologies that stands out are Home Care Attendants, General Duty Assistant, Assistive Care Attendants, Bed Side Assistants, Care giver,

Patient attendants, Geritaric Care Professionals and also local names such as Bua in many case scenario. This varied range of names have been delegated or used by the agencies as per their own convenience and how they look at duties provided by the health care aides.

The terminologies used and how they have been defined is further analysed in the study through the typologies. The researcher found these categories namely, Online service providers, Private for profit companies and Private not for profit companies, The Placement Cells, Training institutes. There is another segment of workforce which is also mentioned by Schneider (2005) to be most unregulated in the context of USA and that is the category of self-employed workforce in case of the present study.

The online service providers seem to be one of the exclusive categories in Indian context. On the advent and expansion of online marketing strategies, this way has become very crucial. These are companies that have been involved in providing range of clinical and non clinical services at doorsteps including home health care for assistance in daily living. They use terminologies such as home care attendants, general duty assistants, and assistive care attendants. The duties as divided for this section of workforce are to provide assistance to patients or elderly. The assistive care is defined as taking care of health and hygiene of the patients, adjusting position of the patients to sit upright, help in movement.

Amongst the other category of agencies the researcher identified private industries that are both for profit and not for profit in nature. The researcher further finds that the business network forecasts massive private investment in Indian market both from foreign and Indian business houses. There is a sense of competition as well as collaboration within these private companies. These companies are using multiple strategies to build their brands in the market. The big brands such as Max Hospital and Fortis are creating its own strategies through collaboration and merger with smaller private companies, government bodies for recruitment and also creating its own customised packages of home health care. These companies often call their health care aides as general duty assistants. The work entailed is again assistive in nature. These companies, as

derived from the web based data in previous chapter discusses about customised health plans which is indicative of change in nature of work performed by health care aides different from patient to patients. Additionally these domestic companies' focus is very different from private foreign network and it focuses on multiple kinds of services ranging from end of life care, post hospital assistance in its care packages.

The case study from the research showcases how the foreign based companies like Globe Bonitus are on the run to establish its own brand. The company has come with the mission of only focusing on geriatric care and thus also call its workforce Geriatric Care Professionals. This is defined more in terms of skill full work assisting elderly for their well-being, which includes nutrition, helping them to cope with issues such as loneliness and also to take care of other health related aspects.

The researcher further finds an existence of private not for profit agencies as well in providing home health care but their presence is not massively seen in the scenario of home health care industry. In India the not for profit companies are not connected to national health programs and work as registered societies. The case study used in the research and also drawn from web based analysis shows, notably the palliative care networks are also working as non-governmental organisations. However to add further, it is not necessary that not for profit companies work in uniform manner and have common terminologies used for their health care aides. The researcher finds some of the not for profit companies work in collaboration with palliative care home. There are other palliative care homes also who are working as not for profit companies or registered as societies have designated home health care teams, and health care aides are part of such teams.

The researcher also found that the training networks are very important parts of the care network. The present study showcases that training networks in India however do not provide a standardised uniform degree for health care aides unlike many other western countries i.e certified nursing assistance, mentioned in Foner (1994). These training institutes also differ from each other in its functions. The two case studies of St Stephens Society and NISD

imply that the modules and selection criteria of these institutes are not uniform. Even the intentions for running the training programs are also very different from each other. The St Stephens society whereas is much more concentrated in livelihood generation for women from Sundar Nagri Community, the NISD's main focus is to build more human resources to address the care gap for elderly population deriving from the mandates in National Policy on Elderly (1995). Both the training institute also use different terminologies for health care aides, on one hand NISD calls them bed side assistants, the St Stephen society use terminologies such as health care workers, care workers or bua; a localised name. Thus the study has derived that the training institutes do not generally work in consistent, uniform ways. Both the institutes however also have placements but do not follow similar patterns, the St Stephens places the health care aides directly with families and the NISD indeed collaborates with many companies and organisations for placements.

The networks of care agencies also include placement cells, very common feature in Indian market for home health care. Many of these placement cells are not registered as companies or societies. The study shows that the placement cells use multiple terminologies to refer to health care aides. They are called home care attendants by few and a range of other terminologies such bed side assistant, home care worker are used for this category. The placement cells often do not have a much defined work profile of the health care aides and hence it varies from client to client.

Moving further there is another set of health care aides who are not regular part of any agencies. They may or may not work in collaboration with the agencies mentioned above. The study shows that a majority of them finds work through contacts in private hospitals, and referring to Neetha (2004) through social networking. There is a presence of such category of health care aides also in western context who come from coloured races and are unable to enter legal employment system mentioned in studies by Stacey (2006). Likewise in this case as well there is a presence of self employed health care aides; however the study shows there is a variation even within these categories. There is a unique category of health care aides who play role of

care givers occasionally. The domestic workers fall in such category and they keep fluctuating from one role to another. The other kind of health care aides are also fluctuating from one kind of work to another and these are mostly nurses who often find the nature of nursing work much more rigorous and less paid in comparison to care work.

These multiple range of care workers and wide range of terminologies, job definitions depict the informal nature of care industry at present. The literature in the context of USA and other countries showcases that care giving industry has some sort of uniformity which is not present in case of India. Based on web analysis and primary data and the findings of the present study discussed above, one can see an extensive diverse network. The care giving process although right now is going through this confusion around terminologies to be used and also lacks uniformity and regulation, the researcher finds a massive presence and influence of private care networks in shaping of the industry.

3.2 Regulation of the Industry

The home health care industry is highly unregulated in Indian context. To draw a parallel to scenario in Europe, although there is a presence of regulative measures to some extent there are problems when it comes to self employed and migrant health care aides as shared by Bettio et al (2006). Similarly Schneider (2003) also shares such issues for self employed and migrant health care aides in USA. They further argue that such unregulated spaces lead to more exploitation of health care aides in terms of their wages and working conditions.

The researcher finds that there is hardly any regulatory system for the care giving agencies in India especially for placement cells and self employed categories of health care aides. The labour law that is commonly followed by some of the agencies such as private for profit, not for profit and training institute is minimum wages act (1948). As far as registration is concerned many of the private companies are registered under companies Act (1956) and the not for profit networks are registered as societies (1861). The online service portals are also often registered as business companies as implied from

the web based analysis. The placement cells are often counted as defaulters and the present findings show many of them actually have never followed any standard laws for wages and working conditions.

There are no laws in specific reference to home health care work creating problems for the self employed categories. Most of the worker who avail work through private hospitals, placement cells, or social networking often is not paid their due wages. The health care aides with families as direct employer are dependent on ethics and values of their employer for right wages.

As the whole industry is unregulated, there is an also massive issue of health care aide not being able to come together as a union. Stacey (2006) suggests that the unregulated nature of care work agencies leads to more exploitation of health care aides. Aronson and Neysmith (1996) discuss how this differential wage system and working processes create problems for health care aides to come as union in USA. Further, Perappadan (2013) also argues that the lack of adequate labour laws in India for health care aides and absence of lobbying for better working conditions is leading to massive exploitation of this workforce.

3.3Commercialisation of Care

The literature review indicated that post liberalisation phase and WTO agreement has created space for global exchange of trade and services (Sykes, 2008). This also led to many changes in developing world, creating new developments in health sector. One of the developments was definitely the migration of large workforce such as nurses to developed world (www.migration.org).

Health care sector in India has gone through a massive change with reforms and the change can be seen with more and more private players being present in deliverance of health care (Bali, 2015). As argued the care industry has also showed its privatised nature with projection of huge profits earned by the private companies.

It was assumed that as care industry is in very nascent stage right now the extent of private bodies would be limited. The finding suggests that this

privatized drive has been supported by state as well in the form of collaboration with these companies for training and provisioning of human resources. In this case the skill India program and NISD administered training programs under the aegis of Ministry of social justice are significant. The present study derives important evidence regarding privatisation of home health care industry. The web analysis showcases the forecast related to estimated growth rate of this industry and secondly the foreign investment that is pouring in the sector. The data shows an investment of amount of \$ 277 million by private companies in the year 2014 from internal big health care companies such as Max and also external foreign companies (www. Yourstory.com). The scope for foreign investment also has opened up more for home health care in 2013 with bilateral collaboration between India and countries like United Kingdom (www. gov.uk.)

Another emergent theme derived from the web based analysis is new forms of investment in home health care work. In this case the entrepreneurship model based on the idea of start-ups has covered a major portion of the market. Indeed they have been able to draw attention of foreign investment as well as large business houses of India such as Dabur.In fact the private hospitals such as Max are also promoting privatized home care, through collaboration with start-up companies to enhance its marketing strategies. This new form of merger and collaboration is creating combined profitability for all the stakeholders. In western context, review of literature does not show any investment of foreign companies which has become a common feature in India, as discussed in the chapter (3) mapping care agencies.

As far as commercialisation of home health care is concerned a trend of customized services can also be seen catering to specific needs of the clients (for example separate services for NRI, high paying clients). This feature has not been found when it comes to home health care in context of other countries. The evidence can be found in the web based analysis of data and also the primary interviews. The further scrutiny into the study shows that this derives from the principle of private entities which finds it crucial to meet the customised need of clients. This however unfortunately is not reflected in the training process of the health care aides. More than 50% of the health care

aides have received training on basic human anatomy and also soft skills. However none of them have reported learning about customised home health care plans. They further noted that this enhances the work burden of the health care aides.

The placement pattern opted by the private home health care agencies depicts their intention of creating a profitable industry. It is often noted that the private bodies such as Max hospital, online service providers actually have focussed more on hiring of supporting managerial bodies. The companies generally rely on online advertisement portals for recruitments. The key informants from private care agencies stated that it is necessary to hire such workforce to boost businesses. The companies generally do not invest in hiring health care aides through this portals and it is often through word of mouth, already existing networks or hire from training institutes such as NISD.

Significantly, the information for training or courses for home health care is available on the media forums such as websites, which are not often accessible to migrant workers, SC communities and uneducated sections of the societies who then often turn to unregulated and underpaid sources of employment. It is narrated by a majority of the respondents that these placement cells hire in bulk from different parts of the country and places them with various families as domestic maids and care workers. As the placement cell bills still not passed (http://ncw.nic.in) there are lot of evidences of abuse and exploitation in such hiring processes. Thus the whole model emphasises more on profitability and pays very less attention to safety and security of health care aides in hiring process leading to exploitation. Notably bodies like NISD (that is working under the aegis of Ministry of Social Justice) although is working towards producing more human resource to combat care gap, they hardly are concerned about creating a larger and more accessible training and recruitment systems.

3.4. Socio-economic profile of the Health Care Aides

This section will look at findings on socio- economic characteristics of health care aide and how a certain socio-economic categories have more presence in home health care work. To draw a parallel in western context, a majority of

population who opt for such occupation are of migrant status and are in dire need of work (WIDE, 2005). Sykes (2005) further notes exploitation at the hands of private agencies of these migrant workers. The discussion above indicates the presence of global care chain (Hoschild, 2000) and how developing nations have been acting as supplier to fulfil the need of such workforce in developed world.

Gill (2004) also added to the argument stating a presence of large section of migrant population in already being evolved care network in western nations from developing world. Although the present study could not find workers who are migrating to different countries there is a vehement presence of a community who have migrated to cities in India. A 77% of the total workforce is migrants. The main purpose of migration is not to find care work except the placement cell recruits. In other cases, the migration took place as husbands or families moved to the city for finding better livelihoods. Although there are a few health care aides (26%) who have higher family income estimated at more than Rs 12000 per month, 44% of the health care aides turn out to be sole breadwinners. It is noteworthy that most of these health care aides are women (88%), and have migrated as dependents, later opting for home health care work due to lack of sufficient income sources in the family or loss of job of their family members. 80% of the total workforce is married and 50% of them actually have more than four member in their household implying a heavy economic burden on the health care aides.

Apart from migrant status, a distinct correlation found between certain social groups and unregulated spaces of home health care work. The findings reveal that a majority of the workforce (a total 40% of the workforce) that belongs to SC or ST category works with underpaid networks of placement cells or are self-employed. This implies the inaccessibility to better pay and much organised agencies for these social categories. This also creates an understanding that home health care work which already is very exploitative in nature in organised networks, poses much more challenge for this social categories in terms of bargaining for adequate wages and working conditions.

3.5: Blurring Boundaries

As far as self- employed categories of health care aides are concerned the present study corroborates with findings of Mehrotra (2011) stating presence of domestic workers in home health care work. An 11% of the total workforce is found to be shuffling between work as domestic maid and care giving depending on availability of work. They generally get connected to such working options through known family networks. The other kind of selfemployed workforce is from nursing background that generally uses the connections with doctors or other nurses in private hospitals to acquire a job. A total of 19% of the total health care aides interviewed come from nursing background. This is found to be a distinct feature of home health care industry in India and not present in other countries. The main reason shared for such shift is dearth of work as nurses, extreme work pressure (the number of patients attended is higher in nursing than in home health caring). This indicates vehemently towards informal nature of health care industry and its haphazard growth in the context of India. A dichotomy exists within the industry with many organisations and private bodies creating systems, processes for shaping the industry but a large section of health care aides still being extremely informal and isolated from the organised care providing networks.

3.6 Condition of Work

Lower wages and challenging working condition are major issues universally for health care aides. Schneider (2003) suggests that in USA the health care aides suffer from low wages mostly when they are part of unregulated spaces. This holds true in case of the finding of present study. However the low wages, timely disbursement, extra work hours without pay are major problems for most of the health care aides in India.

The private companies in India have invested both monetarily and strategically on hiring and maintaining the support system i.e the managerial and clinical positions in care work. Indeed the placement processes depicts that the managerial level officers acquire more salary in comparison to the health care aides. Although in private sector and not for profit companies the wages (Rs

12000/- per month) are better than placement cells (Rs2000/-per month), the amount paid to managerial workers are thrice more than what health care aides receive. Thus the health care aides in the context of India shared finding less dignity in this work as they earn extremely less in comparison to their hard work. They reinstate feeling discriminated as the wages are much higher for their superiors despite the fact that they don't carry emotional and physical burden of caring. Foner (1994) corroborates with this finding and discusses on similar issues faced by nursing aides and health care aides in USA.

Additionally in Indian context the key stakeholders who decide on financial matters and management of the industry affirms that home health care work is highly low skilled and it deserves lower payment than others in supporting system. The situation is worse for the placement cells in India where health care aides reported receiving a salary between Rs.2000- 5000 as well. Only 2 health care aides out of 5 actually admitted receiving more than Rs. 5000 as salary per month. Moreover the payments in few cases are often delayed and the health care aides hardly have any legal support in such scenario. The self employed categories of health care aides are at better position than the ones employed through placement cells as they were able to negotiate a salary between Rs 5000-12000 in certain cases. However the self employed health care aides are also not extremely well off or able to gain a better salary in all cases of care work. They face challenges in terms of fixing their wages as often as they have no backup systems to support their negotiations. This extreme pressure on health care aides in terms of low wages is also discussed by Stacey (2006) in her work and how it becomes difficult for self employed health care aides to always negotiate for better pay or earn for extra hours of work.

3.6.1: Exploitation in Care Work

In western context the literature reveals that indeed the health care aides face extreme issues such as burn out, additional work. Foner(1994) states that health care aides go though both emotional and physical fatigue. This argument holds true in case of the present study as well. The health care aides in India suffer a great deal from emotional and physical pain while providing

care work. Additionally they also feel lack of power in decision making for welfare of the patients. Majority of the health care aides felt disrespected by the families of the patients.

The health care aides report burn out issues in the context of India. The fact that for many of the health care aides opting for home health care work is necessary to sustain their families financially, they generally stick to such work despite having a burn out. As stated by Stacey (2011) one of the major reasons for burn out of the health care aides are extra work pressure, working hours and the fact that they do not even receive the right amount of wages. This leads to a massive frustration amongst the health care aides. The present study also showcases that a majority of the health care aides in India are unsatisfied and feel overburdened with work and less pay. Data from the present study showcases that 66% of the total health care aides have been involved in providing multiple kind of care work, thus facing a newer challenge every time. Nearly 41% reported having a job for less than three months for not being able to cope up with distress and burden of care work. They also share how often the patients or the families remind them that they are conducting a worthless dirty work hence commands no respect.

To add further as most of the health care aides are women the present study shows that they have dual burden of care. Care work which is considered as labour of love is also expected from health care aides in their individual families. A major number of health care aides state acquiring very less support from in-laws or husband when it comes to providing care at home to children or an ailing person. The health care aides are also often expected to engage in other household duties. This leaves female health care aides in a very precarious situation as they often can't leave work due to financial reasons and are also expected to perform equally well in taking care of her family.

3.6.2 Lack of freedom of Health Care Aides

The families who opt for services of health care aides are often not aware of their work prolife or chose to ignore. Majority of the health care aides (78%) reports having difficulty in dealing with families. They also report lacking freedom to make decisions about the patients' well being and feel unsupported

by the care giving agencies. Foner (1994) also suggests similar issues for the nursing aides in hospitals and that the bureaucratic systems are so strong in the context of care industry in USA that it seldom gives space to nursing aides in decision making process. In case of India as well most of the decisions are taken by managerial authorities or clinical workforce not including opinions of health care aides. Thus they often are left out in decision making in care paradigm although they play an extremely important role in managing daily lives of patients. The health care aides in the context of present study are also asked to carry other household tasks which do not fall under the ambit of their duties. This confusion that exists in the families about role of health care aides is also not cleared by the agencies many a times. The employees of placement cells shares how their duties almost fluctuate between taking care of household tasks for the entire family and managing patients.

3.6.3: Burn out Issues

The other major issue faced by the health care aides is that of burden of companionship. Stacey (2011) also narrated in her work how health care aides often feel emotionally burdened as they stay with the patients more than designated hours. They express being emotionally connected to the patients and not being able to cut off from that emotional fatigue once the assignment is over. This companionship most of the health care aides believe to be necessary and an organic process as narrated by Stacey (2011).

In case of the present study as well the health care aide shares being emotionally connected to the patients. In the narratives they state how their work is more than just taking care of daily activities of living for patients. It expands into their personal life and these patients' life become inseparable from their own. This also leads to frustration when the health care aides feel helpless in convincing family members about certain emotional needs of the clients. Also majority of health care aides believe that the aspect of entering into a household and becoming part of their life is most difficult. The main reason behind is non acceptance of health care aides with dignity and their non-inclusion in important matters related to welfare of the patients.

3.7Gendered Work

The findings from the present study reinstate the theoretical framework that care work is feminine in nature. In the case of present study 88% of the total workforce is women. Significantly the minimal number of male workers added, that it is also a strategy of the companies to retain feminine traits of care work by hiring more number of women. The belief that women have inherent capacity to care is also seen to be present when it comes to family care givers in India. Re-emphasising on the argument of Brinda et al(2014), that women are core in care giving, the present study finds that majority of family care givers are women. Adding further, an understanding is also derived based on data that the shift from unpaid to pay care took place as women move out of household for other work.

However the care giving agencies in the context of the present study hired majority of women as care workers. There are few training agencies such as St Stephens Society that deliberately promoted participation of women in home health care work to provide more economic opportunities to women. The other agencies however believes that the emphasis is never on hiring only women as health care aide, but as this work aligns with caring, an inherent quality of women, their presence is more. Moreover they also believe the work is considered unsuitable by many men due to its low wages and undignified nature.

The gender notion of home care work can be further scrutinised in terms of the section of women who opt for this undervalued work. Little (2005) states that the provisions made by welfare states have paved the path for women to opt out of household work and enter into paid work. However it is not so that every woman acquired a chance to enter into better paid jobs. Stacey (2006) showcases that in western countries Hispanic and Black women fill majority of the health care aide workforce owing to economic hardship. In the context of present study the women who form this workforce are mostly migrants, sole bread winners opting for care work for sustaining families. Although majority of the female workforce belongs to general category it is noteworthy that the women from scheduled caste (13%) are part of extremely unregulated and

underpaid spaces such a placement cells or are self-employed. Notably the training institutes (87%) are more accessible for women from general categories and also from higher income families.

4. Public Health Implication

There is a significant need of understanding growth of home health care industry for public health as home health care is a very important component in the continuum of tertiary care. From the perspective of public health, the entire home health care work holds significance, as it indicates efficacy of health care systems in dealing with post hospitalisation or end of life care situations. The present study showcases the overall inclusion home health care is not included in public health paradigm. There is a vehement lack of such support systems for the patients and the family in the government hospitals. Thus the presence of private bodies has become immense in delivering such home health care leading to privatisation and marketisation. Although there is a presence of palliative care network in India as shared in Chaubey and Aarti (1999) and corroborated by present study, there is very less awareness and access to these services. Deducing from the web based analysis AIIMS and hospitals like Ram Manohar Lohia although has access to such palliative care networks; their numbers are very low as compared to massive need. There is growth of private networks for provisioning of home health care in past decade. However these provisions can only be accessible to a few who are capable of paying a price. There is a need of looking at importance of home health care in public health which has been avoided for long considering it to be a task of families.

The present study also suggests that the state does recognise a care gap, such as in case of elderly and created bodies like National Institute of Social Defence under the aegis of Ministry of Social Justice to produce more human resources. But at the same time the present study also further reflects how this institute, actually has promoted privatisation by collaboration with private companies for employing the trained health care aides.

The other public health implication apart from negligence of health systems to provide home health care is how India can play a role in filling the global care gap. The global care gap is huge and a majority of western countries report need for geriatric and palliative care givers. Migration of a major health care workforce has become a concern for many developing nations. Hoschild (2000) coined a terminology i. e Global Care Chain to define this phenomenon of global transaction of paid or unpaid caregivers' workforce across globe. This is a theoretical concept coined to refer and understand the work of a migrant category of women who move from one nation to another as nanny or a home health care aides and live in with the families .Although there is a critic of this theory coined by Hoschild (2000) as it leaves out women who are from privileged background and do not migrate to another countries owing to economic hardships and opt for care work for sustaining their families. The present study has taken into note the concept of global care chain to understand the migration of health care aides from India. While stating that although there is no presence of health care aides in the respondent category who are migrating or have migrated in past, some of them aspire to do so. Most significantly as there is a presence of international organizations such as Globe Bonitus and many other foreign based entities, this seems to be a possible future direction for Indian health care industry. The other factor that should be noted here is that the category of self employed health care aides, also comprise nurses who are aspiring to migrate to developed nation in future to gain better earning.

Thirdly the present study also questions the existing human resource crunch in public health systems. The study interestingly finds that there is a shuffling of workers within the health work force due to lack of adequate opportunities. Thus many nursing professionals actually have joined as health care aide, although skill wise both the work are very different from each other. Similarly the study also finds presence of domestic maid working as health care aides. The training for this category of health care workforce is absent showcasing serious concerns of home health care scenario in India. Significantly as discussed in Vajpai(2014), there is a dearth of workforce in public health service systems and also overloading of work on existing workers. The present study finds resonance with this argument as the health care aides from nursing backgrounds indicated inefficacies of the public health service

system and implied that the overloading and underpaying work has resulted in a shift to care work. There is a need to also note the overtly exploitative nature of private hospitals for nursing categories. Thus the blurring boundary that is present in home health care giving in India reinstates the lacunae in our health service system in terms of human resources and attention paid to strengthening the same.

5. Limitation of the Study

The researcher could not explore the aspect of migration in the industry. There was not much data for outward migration from India to other countries. Though there is evidence of foreign investment, the migration aspect was not covered. It would be an interesting area to explore as many of the care aides also expressed the intention of going abroad (specially the trained categories). This is an interesting area for future research as movement of care workers from one country to another exists as global phenomenon.

The second issue that is limitation is the inclusion of hospice centre as a case study as permission could not be obtained. Although the researcher could observe at one of the hospice care centres, not much narration could be collected regarding ethics and values of such system as opposed to commercial values.

The other area that is left unexplored is entrepreneurship model, which is capturing a large portion of the market. These start-up companies are an interesting model to study as they are creating benchmarks, standards for the care work business. Thus a study exclusively to understand this model would be helpful.

6. Conclusion

To finally conclude the care industry in India has been evolving in last one decade and also has gradually expanded to smaller cities (chapter 3). There is a huge potential seen in India's market for home care work (chapter 3). But care work still remains exploitive in nature with diversity and unregulated spaces. The concern of health care aides is hardly taken into consideration in any of the care networks. The study helps in opening up scope for further

exploration in to the area of paid care work which has found its existence in India for almost last 10 years. The care gap is a global phenomenon and there is a huge shift globally when it comes to nature of care provisioning. The study explored data on the role of family and communities in care work and sees how it has dissolved with time as the economic and family systems changed. The families were no longer a joined unit in many cases and they moved away from each other for better jobs and lifestyle. The rise of elderly population also became a concern in developed and developing nations. Women who were traditional care givers as per Indian family value systems could not bear the burden of caring owing to new economic choices. This added to care gap globally and also in India versus the rising number of elderly and terminally ill patients. Ironically the care industry developing in India and globally retained the feminine nature of care work with majority of workforce consisting of women. The study also further notes how the care work industry is filled with large number of migrants, internal migration for India and cross country migration for other countries. These migrant populations who come to cities with families or looking for a job opt for anything that helps in economic survival, in this case home health care work. The Indian context however shows how within care giving, the better paid jobs and training opportunities are available for women with higher family incomes. Home health care work is extremely undervalued for both trained and untrained sections. However within these categories evidently the untrained self employed and health care aides appointed by placement cells have lowest incomes. Notably in Indian scenario and also in western context the labour laws are not able to cover these categories of health care aides. India additionally has very inefficient labour laws to deal with issues of exploitation in home health care economy. There is also no attention paid from the public health systems to recognise the need of home health care and its provisioning.

Amidst this the study showcases how the private industry is profiteering from this care gap and absence of an efficient public health system in India. There are stakeholders both foreign and domestic who are trying varied combination and permutation to earn best profit. In this process definitely some sort of care provisioning is being carried out but as the section on burn out issues and the experiences of patients entail, it is hardly patients' well-being oriented. The health care aides whose skills and opinions are important for the welfare of the patients, elderly, are not included in the home health care programs designed by these networks of agencies that exist in India.

Bibliography:

- Rosenberg, J P Bullen T Maher K (2014) "Supporting Family Caregivers
 WithPalliative Symptom Management: A Qualitative Analysis of the
 Provision of an Emergency Medication Kit in theHome Setting" American
 Journal of Hospice and Palliative Medicine, vol 32,
- Mishra et all (2013) Diabetes Cardiovascular Disease, and Chronic Kidney Disease in South Asia: Current status and Future Directions"Bristish Mdical Journal vol.2
- Stewart H. (2013),"UK women remain concentrated in lower-paid work, figures show" *The Guardian*, vol 13.42
- Perrappadan B. (2013), "Nobody to care for the care givers, , necessary but expensive", The Hindu
- Bhatnagar G. (2013), A project to pilot the lives of those in need ", The Hindu
- Ganesh, U, (2013)," Domestic work in India", Searchlight
- Huber (2012) "Delegation of childcare as a corner stone of children's interethnic relations" vol.19, Sage publications
- Abraham A. (2011), "A community Approach to Palliative Care, impact
 of neighbourhood network in palliative care, on quality of life of Cancer
 Patients, Kerela, India", Achutha Menon Center for Health Science
 Studies, Trivandum
- Nassbaum M (2011)," Capabilities as fundamental entitlements: Sen and Social Justice" Feminist Economies, vol.10
- Stacey L. (2011)," The Caring Self, the work experience of Home Care Aides",

- Mehrotra S.T (2010)," A Report on Domestic Workers: Conditions, Rights and Responsibilities, A study of part-time domestic workers in Delhi", Jagori,
- Palriwala R, Neetha, N., (2010), Care arrangements and bargains:
 Anganwadi and paid domestic workers in India International Labour Review, vol.149
- UNRISD (2009), "The Political and Social Economy of Care, conference report" United Nation Research Institute for Social Development
- UNRISD (2009), "The Political Social Economy of Care", Columbia University, New York
- WIDE (2009), "We care, Feminist responses to the care crisis", University of Basel, Switzerland
- Chavance B (2009)," Institutional Economics" London, New York: Routledge
- Ingle G., Nath A. (2008), "Geriatric Health in India: Concerns and Solutions", *Indian Journal of Community Medicine*, vol. 33
- Hirschmann N.(2008) Mill, Political Economy, and Women's Work, The American Political Science Review, Vol. 102,
- Misra. J., and Buddig M. (2008) "How Care Work Employment Shapes Economy in a Cross-National Perspective" United Nation Research Institute for Social Development
- Murray. S, Aziz. A, Lynn. J (2008)," Palliative Care beyond Cancer" British Medical Journal, vol.336
- Palriwala R., Pillai N. (2008), "The Political and Social Economy of Care;
 India Research Report 2" United Nation Research Institute for Social Development

- Dias. A.(2008)," The Effectiveness of a Home Care Program for Supporting Caregivers of Persons with Dementia in Developing Countries: A Randomised Controlled Trial from Goa, India" http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone. 0002333 accessed on 11th January, 2014
- Sykes A (2008), "International Cooperation on Migration: Theory and Practice"
 https://lawreview.uchicago.edu/sites/lawreview.uchicago.edu/files/uploads/80_1/12%20Sykes_SYMP.pdf
- Browne, V. C., Braun L.K., (2008), "Globalization, Women's Migration, and the Long-Term-Care Workforce, *The Gerentologist*, vol. 48
- Chaturvedi S.K. (2008), "Ethical Dilemmas in Palliative Care in Traditional Developing Societies, with Special Reference to the Indian Setting", *Journal of Medical Ethics*, vol. 34
- Lacey J., Queen S. (2007), "Palliative Care: A Public Health Priority in Developing Countries", Journal of Public Health Policy, vol. 28
- Mazurkiewicz A (2007)"The concept of care in institutional and feminist economics, and its impact on public policy https://www.aeaweb.org/conference/2015/retrieve.php?pdfid=621accessed on 12th June, 2016
- Anne C. E (2007)," Home Health Aide Training Manual and Handbook", I Universe
- Clark (2007), from margins to centre: a review of the history of palliative care in cancer, Lancet, vol. 8
- Smith K., Baughman R. (2007)," Caring for America's ageing population:
 A profile of Direct care work force" Monthly labour review. Bettio.

 F.,Simonnazi

- ,A., Villa.P.,(2006), "Change in care regimes and female migration: the care drain in the Mediterrenian" *Journal of European Social Policy*, vol.16
- Stacey C., (2006), "Chapter 8, Finding dignity in dirty work: the constraints and rewards of low –wage home care labour", The Social Organisation of Healthcare Work, pub, Blackwell publishing
- Sallnow L., Chenganakkattil S. (2005) "The role of religious, social and political groups in palliative care in Northern Kerala", *Indian Journal of Palliative care*, vol. 11
- Russ J. (2005), "Love's Labor Paid for: Gift and Commodity at the Threshold of Death" *Cultural Anthropology*, Vol26
- Kumar S. and Numapeli M. (2005)" Neighbourhood network in palliative care" *Indian Journal of Palliative care* vol. 11
- Tronto J (2005), *The vicious cycle of privatised caring, Socializing Care*, published Oxford, UK
- Little D.(2005), From Giving care, to taking Care, Negotiating care Work at Welfare's end, Socializing Care, published Oxford, UK
- Hamington M., Miller D., (2005), Introduction: A Modern Moral Imperative, Socializing Care, published Oxford, UK
- Gill. S (2004), Towards a Stark Utopia? New Constitutionalism and policies of globalization Global Tensions: Challenges and opportunities in the world economy, Routledge publication
- Howes C. (2004), Upgrading California's home care workforce, the impact of political action and unionization, Bekerly Institute of research on labour and employment, University of California
- Misra J. (2003), "Caring about Care" Feminist Studies, vol.29

- Fuzy J. (2003), "The Nursing Assistants Handbook", Hartmen Publishing
- Seamark D. (2000)," Palliative Care in India", *Journal of Royal Society of Medicine*, vol. 93
- Hochschild, A. R. (2000) "Global Care Chains and Emotional Surplus Value" in Hutton, W. and Giddens, A. (eds) On The Edge: Living with Global Capitalism, London: Jonathan Cape,
- Tyagi D (2000), "Health Sector Reforms in India", http://www.authorstream.com/Presentation, accessed on 12th July, 2017
- Folbre N, Nelson A J (2000), "For love or money or both," The Journal of Economic Perspectives, Vol. 14
- Nassbaum, M C (2000), Love Care and Dignity" Women and Human Development, the capability approach, Cambridge University Press
- Buchan.J.(2000) "Migration of health workers in Europe: Policy Problem or Policy Solution" *International Social Science Journal*, vol 5
- Chaubey P. C, Aarti V (1999) "Planning Consideration of Comprehensive Geriatric Care in India" Journal of the Academy of Hospital Administration, vol 11
- Ramirez et al (1998), "ABC of Palliative Care" *British Medical Journal*, vol. 316
- Valles R. (1998), "Promoting Health promoting women; the construction of female and professional identities in the discourse of community health workers", *Social Science and Medicine*, vol. 47
- Burn G. (1997), Facing Death, New Themes in Palliative care ed open university press

- Bunton. R., Peterson. A., (1997), Foucault's Medicine," Health and Medicine, Pub Routledge
- Bunton.,R.,(1997), Popular health, advanced liberalism, and Good Housekeeping", Health and Medicine, Pub Routledge
- Bakan, B A. Stasiulis D A (1997), Foreign Domestic Worker's Policy in Canada and Social Boundaries of Modern Citizenship, Not one of the family, Foreign Domestic Workers in India, Pub Toronto Press
- Aronson J., Neysmith, S.M. (1996), "You're not just in there to do the work; Depersonalizing Policies and the Exploitation of Home Care Workers' Labor" *Gender and Society* vol.10
- Green K., (1996)," Home Health Aide Training", aspen pub52
- Colen, S. (1995), Like a mother to them, Stratified Reproduction and West Indian Childcare Workers and Employers in New York: Conceiving the new world order: the global politics of reproduction, University California press
- Foner N., (1994), "The care giving dilemma: work in an American nursing home", pub. University of California press, United States of America
- Porter M., (1986) "A Labour of Love: Women, Work and Caring by Janet Finch; Dulcie Groves", *Labour / Le Travail*, Vol. 17
- Abel. E.K (1986) "Adult Daughters and care for the elderly", *Feminist Studies*, Vol. 12, No.
- Hochschild A.R. (1979), "Emotion at work, feeling rules and social structure" *American Journal of Sociology*, vol.85
- Elders help organisation, www.eldershelp.org, accessed on 19th Nov 2012

- http://cancersupport.aarogya.com/shanti-avedana-sadan/blog, accessed on 25th Nov 2012
- SS home Nursing Serviceshttp://www.sshomenursing.com accessed on 23rd Nov 2012
- www.maxhealthacare.in, accessed on 23rd October, 2013
- http://www.gconnect.in accessed on 10th June 2013
- Domestic workers Welfare and Social Security Act 2010, http://ncw.nic.in, accessed on 9th March, 2013
- Palliative Care http://www.who.int/cancer/palliative/definition/en/, accessed on 10th June 2013
- Who cares? Unpaid care work, poverty and women's human rightshttp//www.ids.ac.uk/events/who cares unpaid care work poverty and women's human rights, accessed on 1st November, 2013
- Unpaid Care Work, http://www.actionaid.org, accessed on 1st November 2013
- The International Convention on Migrant Workers and Committee, http://www.ohchr.org/Documents/Publications/FactSheet24rev.1en.pdf accessed on 24th January 2014-01-27
- GATS Mode 4 How Trade in Services Can Help Developing Countries, http://www.migrationdrc.org/publications/briefing_papers/BP4.pdf, accessed pon 24th January 2014
- WHO (2004) http://www.who.int/hrh/migration/en/ accessed pn 20th January 2004
- Murray. S, Aziz. A, Lynn. J (2008)," Palliative Care beyond Cancer" British Medical Journal, vol.336

- Watts J H ,(2015) "Chapter 2; Caring not curing" Gender health and healthcare, Women and Men's experience in Health Care roles", Ashgate Publishing limited
- Russ J. (2005), "Love's Labor Paid for: Gift and Commodity at the Threshold of Death" Cultural Anthropology, Vol26
- Saunders B (2005)" Staff Exhaustion in Home Care, Text book of palliative care, St Christopher Hospice, London
- Jackson L (2005), Team Building, Text book of palliative care, St Christopher Hospice, London
- West (T (2005), Multidisciplirany working, Text book of palliative care,
 St Christopher Hospice, London
- Virdee A (2005), Difficult Family, Text book of palliative care, St Christopher Hospice, London
- Langa, K. M., Fultz, N. H., Saint, S., Kabeto, M.U., & Herzog, A.R.(2002). In formal
- Caregiving Time and Costs for Urinary Incontinence in Older Individuals in the
- United States. Journal of the American Geriatrics Society. 50
- Hassan M(2000), Work-related stress among health care aides in assisted living facilities: A descriptive exploratory study", Nursing University of Jordan
- Chaubey P. C, Aarti V (1999) "Planning Consideration of Comprehensive Geriatric Care in India" *Journal of the Academy of Hospital Administration*, vol 11

- YongJoo Rhee (1997) Formal and Informal care use before death among community dwelling elderly", Seoul National University
- Unalan H et al (2001), "Quality of life of primary caregivers of spinal cord injury survivors living in the community: controlled study with short form-36 questionnaire" International Medical Society of Paraplegia,
- Phillips, V. L. (1995). "Community care for severely disabled people on low incomes"
- British Medical Journal.
- http://www.who.in accessed on 25th December, 2013
- http://www.nahc.org/assets/1/7/10hc_stats.pdf accessed on 2nd June, 2016
- http://www.bls.gov/oes/current/oes311011.htm#nat accessed on 2nd June,
 2016
- https://www.indeed.com/q-Private-Home-Care-jobs.html accessed onn2nd
 June 2016
- http://www.indeed.com/q-CNA-Home-Care-l-New-Delhi,-IL-jobs.html
 accessed on 2nd June, 2016
- http://www.indeed.com/q-Home-Health-Aide-l-Delhi,-OH-jobs.html,
 accessed on 3rd June, 2016
- https://www.naukri.com/patient-care-jobs-in-delhi-ncr, accessed on 3rd June
 , 2016
- https://www.naukri.com/apollo-home-healthcare-jobs-careers-1403050 accessed on 3rd June 2016
- https://www.google.co.in/?gfe_rd=cr&ei=DSc_WJ78LK7v8wf2taqQBA# q=jobs+in+apollo+home+healthcare+limited+delhi, accessed on 14th July,, 2016

- https://www.apollohospitals.com/careers/ accessed on 15th July, 2016
- https://www.glassdoor.co.in/Jobs/Max-Healthcare-caregiver-New-Delhi-Jobs-EI_IE351076.0,14_KO15,24_IL.25,34_IC2891681.htm, accessed on 15th July ,2016
- http://www.maxhealthcare.in/careers/job-openings, accessed on 15th July ,
 2016
- https://www.google.co.in/?gfe_rd=cr&ei=wX08WKzNEajv8wfL6Yj4DQ#
 q=caregiver+jobs+in+max+hospital+,+Delhi, accessed on 29th June, 2016
- http://www.greataupair.com/fastfind.cfm/search/family/careType/seni orcare/countryList/113/stateList/1415, accessed on 25th June, 2016
- https://www.google.co.in/?gfe_rd=cr&ei=MXs8WIX_O7Dv8wfB6Keg
 DQ#q=care+giver+jobs+in+delhi, accessed on 2nd July, 2016
- https://www.google.co.in/?gfe_rd=cr&ei=qHQ8WNikC6nv8wex7JvgA g#q=live+in+caregiver+job+advertisement, accessed on 4th July 2016
- http://www.maxhealthcare.in/careers/job-openings/patient-carecoordinator-2, accessed on 4th July 2016
- http://www.indeed.co.in/Care-Hospital-jobs-in-Delhi,-Delhi , accessed on 3rd July , 2016
- https://www.naukri.com/job-listings-Urgent-Patient-Care-Coordinator-PCS-fortis-La-Femme-GK-II-Fortis-Healthcare-Ltd-Delhi-2-to-5-years-281215002065?src=seo_srp&sid=14796659646250&xp=4&qp=patient %20care&srcPage=s, accessed on 4th July, 2016
- https://www.naukri.com/job-listings-Urgent-Patient-Care-Coordinator-PCS-fortis-La-Femme-GK-II-Fortis-Healthcare-Ltd-Delhi-2-to-5-years-

281215002065?src=seo_srp&sid=14796659646250&xp=4&qp=patient %20care&srcPage, accessed on 4th July , 2016

- https://www.naukri.com/home-care-jo\bs-in-delhi-ncr, accessed on 15th
 July , 2016
- https://www.google.co.in/?gfe_rd=cr&ei=9eUtWMneIfLs8AeEgq7AB
 A#q=health+care+aide+placement+cell+job+ads+in+delhi, accessed on
 15th July 2016
- http://www.indeed.co.in/jobs?q=health+care&l=delhi&matchtype=b&network=g&device=c&devicemodel=&creative=103652055304&keyword=%2Bdelhi%20%2Bhealth%20%2Bc, accessed on 15th July 2016
- https://www.google.co.in/?gfe_rd=cr&ei=Z64sWMHXAarv8weJ3oXI
 BQ#q=health+care+aide++jobs+in+delhi, accessed on 15th July, 2016
- http://www.maxhealthcare.in/careers/job-openings, accessed on 15th July 2016
- https://www.google.co.in/?gfe_rd=cr&ei=IRYsWM_gErLv8wfu6JOY
 BA#q=advertisement+for+care+aides+in+max+hospital accessed on
 15th July ,2016
- http://www.vishwakarmaopenuniversity.org/open_university_online_cours es.php, accessed on 22nd June, 2016
- http://www.alzheimer.org.in/chapters.php, accessed on 20th June 2016
- http://www.aiims.edu/en/news/95-geriatric-medicine.html, accessed on 20th June, 2016-08-04
- http://www.indeed.com/q-Caregiver-l- Delhi,-CA-jobs.html, accessed on 30th June, 2016
- www.quikr.com, accessed on 22nd June, 2016

- http://yellowpages.sulekha.com/home-health-care-services, accessed on 20t June, 2016
- http://www.aiims.edu/en/news/95-geriatric-medicine.html, accessed on 25th June , 2016
- http://www.fortishealthcare.com/india/patient-care-and-services/patientattendant-responsibilities, accessed on 17th June, 2016
- http://www.moolchandhealthcare.com/index.php?option=com_content&ta sk=view&id=686&Itemid=542, accessed on 17th June, 2016
- http://www.cansupport.org/new/our-services/home-care/)., accessed on 19th June, 2016
- http://www.cansupport.org/new/our-services/home-care, accessed on 19th
 June, 2016
- http://www.shantiavednasadan.in/support.html, accessed on 19th June,
 2016
- http://www.cansupport.org/new/our-services/home-care/), accessed on 19th June, 2016
- cancersupport.aarogya.com/shanti-avedana-sadan/blog, accessed on 19th
 June, 2016
- http://www.cankidsindia.org/milestones.html, accessed on 19th June, 2016
- \bullet http://www.giveindia.org/m-1588-indian-cancer, accessed on 20^{th} June , 2016
- http://ardsi.org/ardsichapters.aspx, accessed on 19th June, 2016
- http://ardsi.org/wedemand.aspx, accessed on June 19th, 2016
- \bullet http://economictimes.indiatimes.com/small-biz/startups, accessed on 17^{th} June , 2016

- http://economictimes.indiatimes.com/industry/healthcare/biotech/healthcare/changing-demographics-fuelling-demand-for-home-healthcare-lack-of-medical-care-in-smaller-towns-responsible/articleshow/33755782.cms, accessed on 20th June, 2016
- http://indianexpress.com/article/india/india-news-india/for-a-few-bucks-more-now-get-healthcare-at-your-doorsteps/, accessed on 20th June, 2016
- http://knowledge.wharton.upenn.edu/article/home-health-care-indiasearch-right-business-model/, accessed on 20th June, 2016
- https://www.google.co.in/?gfe_rd=cr&ei=m6emV6urJcKAvATqir84#q=h ome+health+care+companies+in+india, accessed on 19th June, 2016
- https://yourstory.com/2016/05/house-healthcare-startup, accessed on 24th
 June, 2016
- http://www.pramaticare.com/services/assistive-care,, accessed on 20th
 June, 2016
- https://www.zoctr.com/management, accessed on 20th June, 2016
- http://www.portea.com/about-us/, accessed on 21st June, 2016
- http://www.portea.com/about-us/,https:,accessed on 20th June, 2016
- https://www.zoctr.com/management, accessed on 20th June ,2016
- https://www.zoctr.com/value-propostion, accessed on 20th June, 2016
- https://www.zoctr.com/shopping/cart), accessed on 20th June 2016
- http://www.businesstoday.in/magazine/features/entrepreneurs-eyeventures-in-home-based-medical-care/story/202279.html, accessed on 20th June, 2016

- http://blogs.reuters.com/india/2014/02/05/health-start-ups-tap-indias-growing-home-care-sector, accessed on 20th june, 2016
- https://yourstory.com/2016/05/house-healthcare-startup/)., accessed on 24th
 June, 2016
- http://www.ibef.org/industry/healthcare-india.aspx, accessed on 24th June,
 2016
- https://www.apollohospitals.com/patient-care/value-added-services/apollohome-care, accessed on 23rd June, 2016
- http://yellowpages.sulekha.com/home-health-care-services, accessed on 23rd June, 2016
- http://yellowpages.sulekha.com/home-health-care
 services_delhi?q=Home%20Health%20Care%20Services%20review&c=1
 _yellowpages_delhi_s, accessed on 23rd June, 2016
- http://blogs.reuters.com/india/2014/02/05/health-start-ups-tap-indias-growing-home-care-sector, accessed on 22nd June, 2016-08-09
- https://www.gov.uk/government/uploads/system/uploads/attachment_data/ file/311349/Healthcare_UK_India_and_the_UK_LOW.pdf), accessed on 2nd July 2016
- www.zoominfo.com/c/GLOBE-Bonitas/367208691, accessed on 2nd June,
 2016
- http://homecare.bhnhealthcare.com, accessed on 29th June, 2016
- https://www.google.co.in/?gfe_rd=cr&ei=_sagV4r4NZzrugS4hbrQCA#q=
 Ngos+on+palliative+care+)., accessed on 27th June, 2016
- http://www.maxhealthcare.in/home-care, accessed on 29th June, 2016

- http://www.nisd.gov.in/content/128_1_OldAgeCare.aspx, accessed on 23rd June, 2016
- http://www.nisd.gov.in/, accessed on 23rd June ,2016
- www.zoominfo.com/c/**GLOBE-Bonitas**/367208691, accessed on 20th June, 2016
- www.ilo.org, accessed on 29th June 2016
- http://www.improvingchroniccare.org, accessed on 29th June , 2016
- www.wsmi.org > About Self-Care and Self-Medication, accessed on 29th
 June, 2016

Annexure 1: The Wage Distribution in USA

Industry	Employment(1)		Hourly mean wage	Annual mean wage (2)
Home Health Care Services	385,440	29.67	\$10.93	\$22,740
Residential Intellectual and Developmental Disability, Mental Health, and Substance Abuse Facilities	86,380	14.20	\$10.87	\$22,620
Other Residential Care Facilities	18,360	11.26	\$11.30	\$23,500
Continuing Care Retirement Communities and Assisted Living Facilities for the Elderly	95,590	11.08	\$11.06	\$23,010
Individual and Family Services	149,180	9.37	\$10.62	\$22,090

Annexure 2: Top Paying Industries

Industry	Employment(1)		Hourly mean wage	Annual mean wage (2)
State Government (OES Designation)	7,960	0.36	\$13.49	\$28,050
Social Advocacy Organizations	3,050	1.52	\$13.06	\$27,170
Management of Companies and Enterprises	860	0.04	\$12.96	\$26,950
Colleges, Universities, and Professional Schools	(8)	(8)	\$12.78	\$26,580
General Medical and Surgical Hospitals	10,190	0.19	\$12.49	\$25,970

Annexure 3: Cost Estimate of Care Work

Role	Responsibility,	Cost in CHF (
	required skills	Confederation of
		Helvetica francs)
Wife	Reliable, Status	4,000
	provider, back up ,	
	business partner and co-	
	investor	
General Manager	Overview,	2,000
	accountability and	
	running of home	
Mother (full time)	Nurturer, feel good	4,000
	factor, hunger	
	management, love	
	sensitivity to extreme	
	emotional mood swings	
Cook (full time)	Family health care ,	4,000
	innovative meals,	
	balanced diets, know	
	bio-products	
Nanny, child care	First aid, safety, and	4,000
(Full time)	security of future	
	generation	
Nurse (Part time)	Caring for small	1,000
	wounds, loose teeth,	
	sprained ankles	
Psychologist (part	Child psychologist skills	4,000
time)	, race and ethnicity	

Laundry service (Part	Knowledge of all fabrics	15,00
time)		
Ironing service (Part	As above	1500
time)		
Tailor (Part time)	As above	8,00
Driver (Part time)	Driving license	3500
Social Coordinator		18,000
Birth Machine	Body Politics	24,40,000
Hair and beauty	All rounder	3,000
consultant		

Annexure 4: Hours Calculation of Care work

Summary o f informal care	Population type	Hours needed
Study		
Langa et al. (2002)	Incontinent elderly women	10.7
Langa et al. (2000)	Moderat e dementia	17.4
Hickenbotttom et al (2002)	Elderly stroke patients	18.6
Leon et al (1998)	Eldelry in community	17.9
Cohen et al.(2001)	Elderly in community with private long term care insurance and benefits	14.0
Philips V L (1995)	Severely disables in Community	64

Annnexure: 5

Interview Guides:
Health Care Aide:
In this study the terminology "health care aides" implies those who are getting paid for providing palliative care and geriatric care, which is unskilled labour in nature.
Schedule no: 1
Name of the respondent:
Age:
Sex: Female
Educational qualification:
Address:delhi
Religion:Christian
Caste:
Migrant status:
Place of origin: Assam
Place of residence:
Years of experience as health aide:since 2006 9
Whether trained as a health aide:not
Type of care work provided till date:
1. Child care
2. Terminally ill

3. Elderly care

4. All the categories

Type of employment:

Self 2. Placement cell 3. Private hospital 4. Government body 5.
 NGO/ Self help group

S no	The type	The income	Place of work	Years involved
	of work	earned monthly		
1	Child care	2006	Home	
2				
3				
4				

Interview Guideline for Health Care Aide

Trained Health Care Aide:

- 1. Narrate the process in which you entered into care work?
- 2. Narrate your training process as Health Care Aide.
- 3. Narrate each of your experiences as health care aide till date?
- 4. Narrate about your interaction with the employees in each of your experience?
- 5. Narrate your interaction with the client in each of your experiences as health care aide?
- 6 . Narrate if any incidence has happened which is of violence, or misbehavior during your experiences as health care aide?
- 7. Give your daily schedule in each of experiences as care aides?

- 8. Narrate primarily the kind of work you were engaged in each of experiences?
- 9. Narrate your view on care work being termed as dirty work?
- 10. Narrate your experiences of emotional burnout in your work as health care aide?
- 11. Give details of how wages have been taken care of in each of your experiences chronologically?

Live in Health Care Aide:

- 1. Narrate your arrangements for food and lodging each of your engagements?
- 2. Share about how you felt and what has been your experience living with client and their family?

Live out Health Care Aide:

- 1. Can you share your experiences of how you manage household work and care work?
- 2. Can you narrate any experience where you had to stay with your client? (if any)?

Untrained health care aide (Self employed and placement cell)

- 1. Narrate about your experiences in domestic work and how have you shifted to care giving?
- 2. Share the activities you have performed as care aide and a domestic maid. Is there any difference between the two? Please narrate
- 3. Share the process how you find work and negotiate wages with the family or the employing agency?

Annexure 6: Interview Guide (Family Care Giver)

Family Care giver (A person who gives care to ailing, elderly or a child to someone related to him or her)

Schedule no:

Name of the respondent:
Age:
Sex:
Address:
Caste:
Religion:
Education detail:
Whether employed:
Years involved in care giving:
Types of care giving given:
Recent type of care giving:
Family income per month:
Source of care giving:
• How the person whom you are providing care is related to you?
• Why did not you opt for paid care giver?
• What incidences led to you give care?
• Are you willing to continue giving care?
• Do you receive any assistance from others in the family in providing care?

Type of care provided:

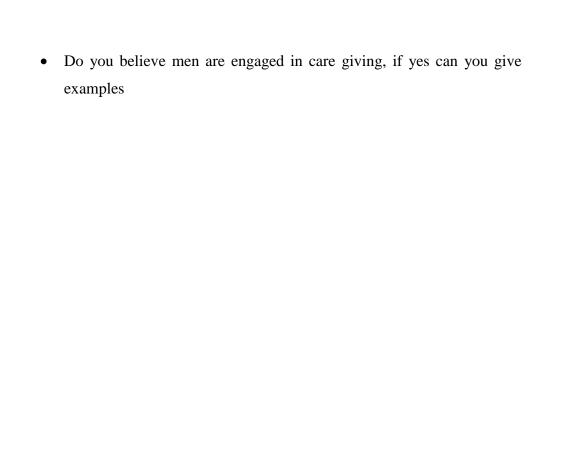
- Can you narrate your day as a care giver?
- Do you find it difficult to manage other activities of your life because of your engagement in care giving
- How do you design your time table for other activities?

Emotional well being:

- Do you feel providing care to the person comes as a duty? If yes why?
- Will you be willing to give up the care giving if you gain a scope for the same?
- Do you feel emotionally vulnerable a times or difficult to manage your emotions at times while giving care work?
- Can you please narrate incidences if any when you have had discomfort in managing activities related to care giving?
- Do you consider care giving as a dirty work? If yes why?
- Do you also counsel for trauma if you are giving care to terminally ill patients?

Female Health care aide:

- Do you believe it is primary social responsibility of women of the house to give care? If yes why?
- Do you think a woman needs to adjust her life and leave other earning engagements to give care at home? If yes why?
- Do you believe it is a common practice for woman to act as care giver even today when woman are engaged in other professional work as well?
- Do you think men also can give care and that he also should adjust his life to make care giving to family members a priority?



Annexure 7: Interview Guide (Key Informant)

Key Informant

(The head of placement cell, coordinator of program at NGO, member of Management authority at Hospital, Main coordinator at government institute, family member that employees paid care giver) Name: Age: Sex: Educational qualification: Caste: Religion: Address: Monthly income: Engagement in other source of earning: a) Yes b) No Years of working experience: Type of agency:

Placement agency b) nongovernmental organization c)Private

Experience of employers:

1. Can you please narrate the process how you entered in care work?

hospital d)Government organization e) Family

- 2. Can you please narrate your view on demand of care work and what has been the growth since you have joined the same?
- 3. What is your view on it being termed as a growing industry?

4. Can you please share about your business plan and how you are connecting care aides to the market?

Profile of Health Care Aides:

- 1. Can you share the following?
- a) The kind of activities performed by Health Care Aide
- b) How are these job profiles defined?
- 4. What is the socio economic profile of those who are willing to apply?
 - a) Caste
 - b) Religion
 - c) Family income
 - d) Religion
 - e) Migrant status
 - f) Place of residence
 - g) Place of origin
 - h) Age
 - i) Marital status
 - j) Sex
 - Can you please narrate the socio economic profile of the families that seek such care services?

Benefits of the industry:

- What do you think are the benefits of such industry in urban Indian context?
- Is this a very good opportunity for the health aides and is there any growth for them in such care industry?

- Do you believe the grow?
- .cidences?
 - Do they report any
 - a)violence or
 - b) Misbehavior,
 - c) Extra work

From the side of those who ask for care aides? If they do how do you tackle such issues?

Government institute:

- Can you please narrate the role of state in providing care and how the government policies contributing to the same?
- What is your view on various other stakeholders (Placement cell, NGO, private hospitals) working intricately in this industry?
- Do you also work in collaboration with them or have any such plan in future?

Family member that employees paid care giver:

- Can you please explain how and why you have opted for Health Care Aide?
- Can you please share your experiences with the Health Care Aide/
 Health Care Aides?
- Do you believe the care aides can render better care giving than a family member? If yes why?
- Can you please narrate any experience when your care aide has misbehaved with the patient or with the family?
- Can you please narrate the process of payment for the health aides?

Annexure 8: Consent forms (Key Informant)

Description:

The study is primarily going to focus on understanding the nature and extent of care giving as an industry in Indian Context. As Care Giving at homes have primarily moved out of the realms of household it is important to understand the work of such paid Health Care Aide as well as role of various stakeholders in growth and expansion of this industry. The study would like to explore the management, wage condition, and aspects of state regulation. Hence the interaction with primary key informants of the institutes involved in recruitment, management of this industry would be crucial.

I am aware of advantages and disadvantages of the research conducted by the researcher. I am willing to take part in the same

I willingly, under no pressure from the researcher-

i)agree to take part in this research and share my knowledge about the work of health care aide, the regulation mechanism , management, maintenance of finance of my own agency (NGO/ Placement Cell/Private Hospital/Government Hospital/Government Institute)

ii) agree to share information about the health care aide employed in my family, our experience with the same and about the wage and working conditions(for family members as key Informants) My consent is explicitly not for disclosing any personal information. The researcher has committed of not disclosing any identity of the respondents.

I have been informed that JNU and the researchers (PI .Ritumoni Das) will take my prior consent before they draw benefits from research based on my interviews.

Signatures		
~		
Subject/patient	Witness	
Principle Investigator.		

Annexure: 9 Consent Form (Institution)

Information for the Organizational Permission:

The study is primarily going to focus on understanding the nature and extent of care giving as an industry in Indian Context. As Care Giving at homes have primarily moved out of the realms of household it is important to understand the work of such paid Health Care Aide as well as role of various stakeholders in growth and expansion of this industry. The study would like to explore the management, wage condition, and aspects of state regulation. Hence the interaction with primary key informants of the institutes involved in recruitment, management of this industry would be crucial.

Therefore the researcher would seek permission of the institutes which are placement cells, NGO, Private Hospital, Government hospital, Government Institute for sharing information about paid care giving through interviewing their key informants.

The following kind of themes would be covered in the interview process

- a) The qualifying criteria and job profiles of Health Care Aide
- b) The socio economic profile of this workforce.
- c) The history of the institute in offering care to terminally ill/children/elderly/ or all these three
- d) The wage, working conditions of the Health Care Aide
- e) The experience of key informants and the reasons for joining this industry
- f) The rules and regulations that governs this industry

Authorized signatory:

Annexure 10: Consent Form (Health Care Aide)

Description:

The study is primarily going to focus on understanding the nature and extent of care giving as an industry in Indian Context. As Care Giving at homes have primarily moved out of the realms of household it is important to understand the work of such paid Health Care Aide as well as role of various stakeholders in growth and expansion of this industry. The study would like to explore the issues of nature of work, wages, and emotional burn out through interviewing the Health Care Aide. The family care givers also would be a part of the study as the researcher would also look into the systems that exist in society for care of terminally ill, elderly and children. This would apply the feminist discourse of care work being tilted towards women of the family.

I am aware of advantages and disadvantages of the research conducted by the researcher. I am willing to take part in the same

I willingly, under no pressure from the researcher-

- (i) agree to take part in this research and share about my job profile as
 Health Care Aide placed in NGO/ Placement Cell/Private
 Hospital/Government Hospital/Home
- ii) agree to share my information about wage issues/ issues related to interaction with my patient / elderly / child/ and their families

My consent is explicitly not for disclosing any personal information. The researcher has committed of not disclosing any identity of the respondents. I have been informed that JNU and the researcher (PI .Ritumoni Das) will take my prior consent before they draw benefits from research based on my interviews.

Signatures		
Subject/patient	Witness	Principle Investigator.

Annexure 11: Typologies Of Health Care Aide

Nomes of			The recent		Definition
Names of	V 1	Names of	The work	Terminology	Delimition
services	Services	the			
		companies			
Online	Private	Portea	These	Home care	This private
service	companies	Health Care,	companies	attendants,	sector use these
providers	1	Help Path	began surfacing	Patientt	terminologies
providers		Homes,	from the time	attendant,	and it implies
		Pramati	2013 and they	General Duty	workers who
			•	•	
		Care,	mostly began as	Assistant,	provide home
		Nightangles	small business	Assistive	care for elderly,
		Care	start ups. They	care	palliative care
		Centers,	offer home care	attendants	and care for
		Health	in range of		patient after
		Above 60,	services. Home		surgery. These
		Zoctre,	care for helping		workers provide
		Heritage	patients with		assistance in
		Health Care	daily activities		managing
		India	•		0 0
		Illula	of living also		personal
			falls in their		hygiene that
			services offered.		includes bathing
					cleaning, using,
					toilets , urine
					cheque etc as
					well as matters
					of activities in
					daily living that
					includes
					adjusting
					v C
					position of the
					patient or
					elderly
					depending on
					capacity ,
					ensuring
					exercise or any
					body movement
					necessary., and
					help patients or
					elderly to use
					•
					devices that
					smoothens daily
					functioning.
	Placement	66 such	These are again	Home care	These
	cells	listed	online based	attendants,	terminologies
		websites	service portals	Patient	are used by
			that use E-	attendant,	placement cells
			Classified	General Duty	in the
				Assistant ,	advertising
			advertising sites	Assistant ,	auverusing

-		1	
	to list their	Bed side	sites. These
	facilities which	assistants	generally define
	include services		a workforce
	of nurses at		who can be
	home and also		hired for Home
	Health Care		care for elderly,
	Aides.		child care, post
	Tides.		hospitalisation,
			palliative care,
			and care during
			injury and
			mental disorder.
			These care types
			are provided as
			per the need of
			the family. The
			nature of duty is
			to primarily to
			take care of
			personal
			hygiene needs
			such as
			changing of bed
			sheets, other
			hygiene needs
			as well as
			helping in
			activities for
			daily living
			which are
			assistance in
			sitting, getting
			up from bed. As
			-
			these categories
			also re involved
			in child care
			(new born and
			toddlers) their
			duties may
			include taking
			care of personal
			hygiene for the
			child, bathing
			feeding.

Private for	Domestic	Private for	Apollo started	Care giver,	The care giver
profit		profit	their company	Patient	or patient
companies		companies	in the year	Attendant,	attendants or
			2014 with an	Home health	home health
			expansion of	Aides	aides are
			Apollo into the		terminologies
			arena of home		used by Apollo
			care with a		Home Health
			range of		Care limited
			specialised in		defining care
			range of		givers who
			physicians ,		work in close
			registered		relation with
			nurses ,		patient's
			physical and		primary
			operational		physician to
			therapists and		develop a
			home health		personalised
			aides working		care plan. These
			closely with		Health Care
			physicians with		Aides work in
			personalised		aspects of
			plan		elderly and
					dependent care,
					post surgery and
					post
					hospitalisation
					care. They
					generally
					provide
					assistance in
					activities of
					daily living but
					also has duties
					as enshrined in
					personalised
					plan prepared
					along with
					primary
					physician

Max	Max began its	General Duty	The word
Hospital	work as an	Assistant (general duty
	extended	GDA)	assistant implies
	company of		that the duties
	Max Hospital.		taken care of by
	They have a		the workforce is
	Home Care Unit		generic in
	who along with		nature. As
	Shine Standard		defined by Max
	housekeeping		hospital the
	company		GDAs are of
	contracted by		two categories
	Max works for		one that takes
	maintenance		care of patients
	and		when they are at
	management of		hospital as well
	home care		as providing
	services. Home		care at home
	Care Unit takes		post
	care of		hospitalisation.
	communication		This includes
	with clients,		care in terms of
	induction of		assisting
	GDAs whereas		patients in daily
	the Shine and		activities of
	Standard takes		living and also
	care of logistic		personal
	and		hygiene.
	administrative		
	aspects.		

International	Globe	Globe Bonitus	Geriatric	This category is
	Bonitus	is Sweden based	Care	defined as
		company and it	professional	Health Care
		began its work		Aides who
		in India in the		particularly
		year 2015. It		attend to
		primarily		population i.e
		wanted to focus		elderly. They
		on aspects of		focus on trained
		geriatric care		geriatric
		which includes		professionals
		clinical services		who can assist
		as well as allied		elderly for
		services		planning well
		ensuring well		being in terms
		being of elderly.		of food,
				nutrition etc.
				These
				professionals
				are supposed to
				be aware of the
				psychological
				and
				physiological
				problems of
				elderly and plan accordingly.
				They are also to
				help in personal
				hygiene as well
				as activities of
				daily living for
				elderly

Placement	Varghese	This agency	Home care	The category is
agencies	agency	began its work	attendants	defined as those
ageneres	agency	in 1996 and it	attenuants	are either nurses
				or women who
		was providing of nursing		
				provide long
		services to		term care. The
		patients		placement
		requiring		agencies
		palliative care,		generally do not
		post		define the kind
		hospitalisation		of work care
		care, care after		aides are
		surgery and		supposed to do
		injury. They		and it can range
		extended their		from bathing,
		services to		cleaning and
		giving		taking care of
		assistance for		any other needs
		daily living and		of the patients
		personal		or shared by
		hygiene through		family. As
		another kind of		derived from the
		recruitment as		data home care
		not all the		attendants
		nurses were		actually do not
		ready for this		have any
		kind of work.		definite job
		The present		profile detailed.
		workforce has a		In this case they
		combination of		are involved in
		nurses and		child care,
		health care aide		elderly care, and
		with other		care for patient
		educational		with mental or
		qualification.		physical
		The placement		disorder. There
		cell also had		is no process of
		workers who		training for the
		have moved to		home care
		this agency from other		
				most case.
		placement cells.		

Training	St Stephens	St Stephens	Care giver,	Care giver here
institute	Society	society is an	Bua	is defined as
		NGO that		those who are
		actually works		trained to
		as a training		provide help or
		institute from		assistance in
		2005. It began		daily activities
		training women		of living such as
		from		bathing ,
		Sundarngar		cleaning and
		Community as		washing ,
		Care givers or		exercise for
		Bua It conducts		patients with
		training on		terminal illness,
		basic concepts		elderly.These
		of health and		care aides are
		illness and also		also given basic
		soft skills,		information on
		values to deal		communicable
		with patients or		and non
		elderly. The		communicable
		institute also		diseases and
		involves care		human body.
		givers from the		The
		training		terminology
		program in St		Bua is used for
		Stephens to		health care aides
		provide		who are
		assistance to		involved in
		mother to take		providing
		care of new		assistance to
		born in maternal		mothers during
		and child		hospitalisation
		delivery unit of		for birth of child
		St Stephens		and after.
		Hospital		

NISD	NISD began	Bed side	The NISD
	working as part	assistants	defines bed side
	of Ministry of		assistant as
	Social Justice to		those who
	provide more		generally
	assistance to		provide
	elderly under		palliative care
	the National		services, crisis
	Policy for Older		management for
	Persons. They		elderly. They
	started as a		train the
	training institute		workforce in
	to increase		behavioural
	human		aspects such as
	resources for		how to conduct
	geriatric care		conversations
	and place them		with elderly,
	in NGOS,		management of
	private .		their loneliness
	companies.		through various
	They had		activities .The
	courses to		bed side
	engage more		assistants are
	and more		trained in
	discussion and		managing
	action on		personal
	geriatric care		hygiene , and activities of
	through research ,		
	counselling and		daily living as well.
	_		Well.
	also provide training for bed		
	side care giving		
	side care giving		

Private not	Palliative	Shanti	Shanti Avedana	Home Care	Shanti Avedana
for profit	network	Avedana	is palliative	giver	actually do not
P			care network	8-1-0-	provide direct
			that has its team		home care and
			of doctors,		are associated
			nurses and		with many other
			counsellors for		NGOs who are
			patients		working in the
			suffering from		field of
			cancer. The		providing home
			palliative		care.
			network focuses		
			on symptom		
			and pain		
			management at		
			their care		
			center. Home		
			care is		
			considered an		
			option when the		
			patient is at		
			final stages and		
			requires		
			comfort of		
		C	home.	H C	TT
		Can support	Can support provides	Home Care Team	Home care team comprises of
			residential care	1 Calli	comprises of doctors, nurses
			for cancer		and counsellors
			patients, but		, care givers
			also recognises		who provide
			the need of		assistance to
			home care for		family members
			patients whose		at home for
			cure is not		patients who
			possible. They		have very less
			have around 25		chance of cure
			teams for such		and would not
			home care. The		benefit from
			can support is a		being in
			palliative		palliative care
	1	1	network and		center. They
			focuses on pain		help family
			focuses on pain management,		help family members to
			focuses on pain management, assisting family		help family members to cope with end
			focuses on pain management, assisting family members and		help family members to cope with end of life
			focuses on pain management, assisting family members and patients to cope		help family members to cope with end of life situations. To
			focuses on pain management, assisting family members and patients to cope with end of life		help family members to cope with end of life situations. To deal with
			focuses on pain management, assisting family members and patients to cope		help family members to cope with end of life situations. To

		Т	Т .
	support (fixing		they come as a
	doctor's		team of doctor
	appointment for		and nurse for
	chemotherapy		clinical aspects
	and other		and counsellor
	treatment),		to deal with
			emotional
	house clinical		aspects.
	services, and		
	also care giver		
	to provide with		
	activities of		
	daily living		
	such as sitting		
	up and turning		
	positions in bed,		
	exercise, as well		
	as personal		
	hygiene. They		
	have		
	counsellors as		
	well who		
	provide		
	psychological		
	support to		
G 111	patients.	<i>a</i> .	TD1 .
Can kids	It has a home	Care givers	The care givers
	for children		are defined as
	who are		those who
	suffering from		provide
	cancer for pain		assistance to
	management		patients at the
	Ç		day care center
			for personal
			hygiene and
			activities of
			daily living.
			They put lot of
			attention to
			empathy as a
			value while
			providing such
			support to
			patients. They
			pay home visits
			and also assist
		i	Lumiliae managa
			families manage
			end of life

				there is very less chance of recovery.
NGOs	Caring heart, cancer patients AIDS association ,V-Care ,Help age India	These NGOs provide assistance in care giving to families directly and also through palliative networks or hospitals. These networks of NGOs work without any profit motives. NGOs like Help Age India also provides services to elderly, however they also provide assistance to families regarding how to take care of daily needs of elderly through their NGO and a help booth in AIIMS Delhi. Apart from that there are care giving NGOs follow the value systems of palliative care networks such as empathy in end of life situations both for families and patients. Their care working team include counselling services , one	Home care attendant, Care giver,	These home care attendants or care givers can be defined as one who engages in provisioning of assistive care for daily functions or counsel families in taking care of daily activities of living for patients.

	<u> </u>	<u> </u>	<u> </u>		
		W	ho can take		
		C	are assistance		
		a	nd personal		
		h	ygiene		
Employed	Private			Care Giver	This is a
through	hospital like				category of care
social	Mulchanfd,				workers who
Networks	family				work through a
Titetworks	Network				method of social
	Network				
					terminology
					used in
					literature for
					domestic
					workers
					(Neetha, 2004) .
					This implies use
					of known
					networks to
					avail work and
					not being under
					any institutional
					or agency
					employment
					directly. These
					care aides are
					not part of any
					agency as full
					time employee.
					They can be
					workers who
					have also
					worked as
					domestic maid
					nurses as well
					who keep on
					shuffling
					between nursing
					and care work.
					The boundaries
					of work is
					blurred in the
					case of nurses
					as they also take
					care of medicine
					and clinical
					aspects as well

		as personal hygiene and assistance in activities of daily living which are key components of care aides' work in other agencies . Similarly the domestic maids also keep shuffling between other household task and care giving.

Annexure: 12 Comprehensive Service packages

Comprehensive Service packages	Name of the Institute		
Assistive care/ Additional care/ Home health aide/Nursing Attendant /post operative care/ care for bed ridden/ elderly care / care packages	Portia health Care, Health Care Home India, Help Path Homes, Pramati Care, Nightangles Care Center, Health Above 60, Zoctre, Heritage Health Care India		
Physiotherapy	Portea, helpathhomes, healthcareathomeindia		
Speech Occupational	Health Care Home ,Pramati Care,Helpathhomes		
Doctor Visit	Portea, Health care Home India, Pramati, Health Above 60		
Hygiene and Sanitation Maintenance	Health Care Home India		
Infection Control	Health Care Home India		
Health record maintenance	Help Path Homes, Portea Health Care, Pramati Care		
Diagnostics	Health care Home India, Portea Health Care, Pramati Health Care		
Equipments	Health Care Home India		
Home Delivery of medicines , household items	Help Path Home, Health Care Home India		
Home based Oncological care	Zoctre, Help Path Homes		

Annexure 13 Advertisements for Health Care Industry

List 1: Home Health Care Services in Delhi (http://yellowpages.sulekha.com/home-health-care-services)
verage Rating 5 out of Sort b Indraprastha Diagnostic Centre, Lajpat Nagar 1
Iome Health Care Services, ECG Scan Centres, X-ray Scan Centers and more
91 11 33236378 No. C-64, Lajpat Nagar 1, Delhi - 110024 - Get Directions Sulekha core3.1
ave to Phone/EmailSend SMS to Business Get Best Quotes
ortlist Relief Physiotherapy, Yamuna Vihar Home Health Care rvices, Physiotherapists for Home Visits
130462777 No. B 1/165A, 10th Street, Bhajanpura, Yamuna Vihar, Delhi - 110053
ulekha score 1.3 Save to Phone/EmailSend SMS to Business Get Best Quotes hortlist Surya Health Care, Shahdara Home Health Care ervices, Physiotherapists for Home Visits 9891329211
^l o. 21/2, Hari om <mark>Gali , Shahdara, Delhi — 110032</mark>
Sulekha score 1.4 Save to Phone/EmailSend SMS to Business Get Best Quotes hortlist Mobile Physiotherapy units, Naraina Industrial Estate
Iome Health Care Services, Physiotherapists for Home Visits

Annexure 14: Job Placement Advertisements

Search, Follow and Connect with top recruiters in your domain
Top of F India's No1 Job Site orm
home health c
Search
Only show Recruiters who \square Have Active Jobs \square Have been Active in the last 3 months
Bottom of Form
Refine Results
Top of Form
Recruiter's Location
(58)Delhi / NCR (44)Bangalore (44)Mumbai (31)Others (24)Hyderabadmore
Recruiter's Role
(124)Company Recruiter, HR Professional (122)Recruitment / Placement Consultant (15)Hiring Manager (6)Others
Functions Hiring For
(40)Pharma / Biotech / Healthcare / Medical / R&D (34)ITES / BPO / KPO / Customer Service / Operations (29)Sales / BD (20)Marketing / Advertising / MR / PR (18)HR / Administration / IRmore
Industries Hiring For
(54)Medical/ Healthcare/ Hospital (34)BPO/ ITES (34)IT-Software/ Software Services (24)Banking/ Financial Services/ Broking (17)Pharma/ Biotech/ Clinical Researchmore
Levels Hiring For

(109)Senior Management (73)Top Mangement (60)Middle Management

(naukri.com

Zionon Health CareStaff Nurses For Hospitals and Home Health...Zion Health CareGurgaon

Skills/Roles I hire for:

Communication Skill, health care experiance, Bpo experiances in any, Staff Nurse, Bpo Staff, Real Estate and Property, Back office assistant, Requirements

1 active jobs | Last active on 15-Mar-2015

Follow293 Followers

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Ravi ShankarChief Coordinator Ashray Outreach ServicesAshray Medical CentreDelhi

Skills/Roles I hire for:

Patient Care, Home Healthcare, Non-medical Nursing, Community Healthcare, Patient Attendant, Patient Caretaker, Fresher General Duty Assistant, Fresher

2 active jobs | Last active on 26-Nov-2016

Follow13 Followers

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Ashvini HemneHealth Education LeadAAA Healthcare Consultancy ServicesMumbai

Skills/Roles I hire for:

Paramedical Training, Content Development, radiology, general duty assistant, home health care, soft skill development, Disaster Management, emergency

1 active jobs | Last active on 14-Sep-2016

Follow 10 Followers

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NeelKamalHR-ExecutiveHelp4u Pvt LtdFaridabad

Skills/Roles I hire for:

Nursing Staff ANM, GNM, ICU Staff, MPHW, home health care, Elder Care, Nurse, Home Health care, ANM, BSc. Nursing staff

1 active jobs | Last active on 06-May-2015

Follow76 Followers

Send Message



Mr K K AlviHuman ResourcesDigital Healthcare StartupDelhi

Skills/Roles I hire for:

Accounting, Clinical Research, Dietetics, Dietitian Activities, Diet Counselling, Diabetes, Data Entry, Hospital, Front Office Management, Back Office, Back

2 active jobs | Last active on 08-Dec-2016

Follow448 Followers

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Sushma PatilNurse CoordinatorHello Health Services Private LimitedMumbai

Skills/Roles I hire for:

Nursing, Attendants, Caregivers, Nurse, Wardboy, Home Care

1 active jobs | Last active on 24-Nov-2016

Follow2 Followers

Send Message



DR HEMLATADIRECTORINDIAN INSTITUTE FOR JOB PLACEMENTSMumbai

Skills/Roles I hire for:

Nursing Assistants, Home Care, Ot Assistant, Housekeeping, Ward Boy, Community Survey, First Aid, Vaccination, Pharmacy Assistant, Bedside Assistant

2 active jobs | Last active on 09-Sep-2016

Follow37 Followers

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(naukri.com

Lynn Marie HenryBusiness Development ManagerHealth Serve Home HealthcareUAE - (Dubai)

Skills/Roles I hire for:

English, Home Care, nurse

1 active jobs | Last active on 12-Nov-2016

Follow12 Followers

Send Message



Ms MollshreeAssistant Manager Human ResourcesHealth Care At Home IndiaNoida

Skills/Roles I hire for:

Customer Service, Customer Care, Customer Support, Crm, Telecalling, Healthcare

7 active jobs | Last active on 19-Dec-2016

Follow255 Followers

Send Message



vimalCompany HRPorteaMohali

Skills/Roles I hire for:

Nursing, Required Nurses To Work In Home Healthcare Setup

1 active jobs | Last active on 20-Oct-2016

Follow7 Followers

Send Message



Abhishek Singh TanwarCompany HRHOSPITAL AT HOME HEALTHCARE SERVICES PVT....Delhi

Skills/Roles I hire for:

Healthcare

4 active jobs | Last active on 12-Dec-2016

Follow26 Followers

Send Message



Harikrishnan AVAssociate General Manager Human ResourcesU H Health care Pvt. LtdKerala

Skills/Roles I hire for:

Communication Skills, Sales Planning, Customer Service, operations, nursing, GNM Nurse, BSC Nurse

2 active jobs | Last active on 12-Sep-2015

Follow264 Followers

Send Message



Asif MohammadFounderFriska Home Health CareVijayawada

Skills/Roles I hire for:

Not Specified

2 active jobs | Last active on 06-Dec-2016

Follow14 Followers

Send Message



Juli FrancisHR AdminOakridge IT Solutions Pvt. Ltd. Hyderabad /...

Skills/Roles I hire for:

BDM, BDE

1 active jobs | Last active on 26-Sep-2016

Follow510 Followers

Send Message



Carepur Services LLPCompany HRCarepur Services LLPChandigarh

Skills/Roles I hire for:

Not Specified

0 active jobs | Last active on 03-Nov-2016

Follow7 Followers

Send Message



Latha RaoNational Recruitment ManagerNightingales Home Health SpecialistBengaluru / Bangalore

Skills/Roles I hire for:

nursing, physiotherapy, Doctor Activities, Customer Service, Customer Care,

sales, Corporate Sales, Specialist Activities, Patient Care, Care Giver, Branch

15 active jobs | Last active on 19-Dec-2016

Follow776 Followers

Send Message



Ravi ShankarChief Coordinator Ashray Outreach ServicesAshray Medical CentreDelhi

Skills/Roles I hire for:

Patient Care, Home Healthcare, Non-medical Nursing, Community Healthcare, Patient Attendant, Patient Caretaker, Fresher General Duty Assistant, Fresher

2 active jobs | Last active on 26-Nov-2016

Follow13 Followers

Send Message



Ashvini HemneHealth Education LeadAAA Healthcare Consultancy ServicesMumbai

Skills/Roles I hire for:

Paramedical Training, Content Development, radiology, general duty assistant, home health care, soft skill development, Disaster Management, emergency

1 active jobs | Last active on 14-Sep-2016

Follow10 Followers

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Annexure 15: Course Structure at NISD

Target Group: An individual having graduation and above educational qualification and interested in working in this field.

Aims & Objectives are to:

develop a cadre of frontline skilled/trained personnel of geriatric care provide a comprehensive and scientific knowledge base on various aspects relating to the geriatric care

develop an appropriate aptitude and skill for working with older persons

Course Curriculum broadly includes

Gerontology

Public Policy and Planning

Clinical Geriatrics

Geriatric Management,,

Psychology and Counseling

Research Methodology

Academic inputs include

- (i) Seminar Presentation
- (ii) Dissertation
- (iii) Group Project
- (iv) Field work/Placement

Duration of the Course : One Year

Total Number of Seats: 20

Announcement of the Course in National/Regional Dailies: May/June

Admission into the course in made on the basis Common Aptitute Test (CAT)

held on All India Basis, Group Discussion and Interview

Tentative Commencement of Course: 1st October

Career Prospects:-

The career opportunities for the Post Graduate Course could range from Non-governmental Sector, Government Sector, Corporate Sector and the Academic institutions as:-

Project Director/Programme Managers

Counselors & Consultants in CBO

Associates with RWA and NGOs

Professionals in Hospital Settings

Prospective Faculty Members and Instructors/Trainers in Academic Institutes

1. Certificate Courses in Geriatric Care

Three Month Basic Course for Caregivers /Bed Assistants

Target Group: Any individual having passed 10th standard, having a desire to serve senior citizens.

Aims & Objectives are to:

create a cadre of care giver for having bed care assistance, etc provide palliative care services, emergency and crisis management etc

Course Curriculum includes

Ageing

Health Care

Fundamental Care

Other Aspects

Practical Training inputs include

Field Visits in Old Age Homes/Age Care Institutions for exposure Short term Placement in Hospitals.

(ii). Certificate Courses on Thematic Issues

The Six Months and Two Months certificate courses have been converted into Three Month Certificate Course.

3. One Month Course on Basic Issues in Geriatric Care

Target Group: NGO functionaries and Service Providers

Aims & Objectives are to:

build a comprehensive knowledge base on basic issues in geriatric care enhance their skill and capacities in counseling and management of age care institutions

expose to various situations and innovative approaches in the field of ageing

enhance their knowledge in resource management, advocacy and networking

Course Curriculum includes

Socio-Demographic Dynamics

Public Policy and Planning

Fundamentals of Ageing Care

Geriatric Counselling

Geriatric Management

Practical Training inputs include

Field Visits in Old Age Homes/Age Care Institutions for exposure

Short term placement in Hospitals with Specialized facility for

Geriatric Care

Innovative Projects on Aged

Report Writing and Seminar Presentation

4. Training Programmes on Themes like Geriatric Counselling, Management of Dementia etc.

Target Group: NGO functionaries and Service Providers

Aims & Objectives are to]

Develop and enhance the basic skills in Geriatric Counselling of the Key Functionaries of different NGOs.

Enable the participants understand the various psychological factors related to Ageing.

Orient the participants with various approaches in Counselling for the care of older persons.

Give practical exposure of specialized intervention strategies while caring for the aged.

Create awareness about dementia and its various types

Educate volunteers and Care Givers to identify early warning signs of dementia and early prevention

Enhance the skills of Care Givers in managing elderly with dementia

Training includes

Classroom Sessions (Theory & Practical) on specific topics
Field Visits in Old Age Homes/Age Care Institutions for exposure

5. One Day Programmes

Target Group: PRIs, Teachers, Counsellors, Anganwadi Workers, ASHA workers, School and College Students, Youth

Aims & Objectives are to:

sensitize and create awareness for Bridging the Inter-generational Gap sensitize and create awareness on Maintenance and Welfare of Parents and Senior Citizens Act, 2007

Annexure 16: Wage Modalities in India

Name of the stakeholder	Type of payment
NGO	Mostly paid in cash in the mode of daily payment
Private Hospital	Payment in cheque , PF included
Private Cells	Payment in cash or cheque
Private Companies	Cheque
Self employed	Cash

ETHICAL CLEARANCE CERTIFICATE

INSTITUTIONAL ETHICS REVIEW BOARD Jawaharlal Nehru University New Delhi-110067

IERB Ref. No.2014/Student/58 Name of the Ethics Committee: IERB-JNU Title of the Project Proposal: "Exploring the Growth of Care Industry in Urban India: A case study of Health Care Aides in Delhi" Principal Investigator: Ms. Ritumoni Das c/o Dr. Ramila Bisht (Supervisor and PI) CSM&CH/SSS/JNU Sponser: NA Email: ritumonidas@gmail.com

Collaborators' Name:

Telephone:

FOR OFFICIAL USE

The proposal was reviewed in a meeting held on 23rd September, 2014 at 4:30 PM. The following members were present:

- 1. Professor Shiv K. Sarin, Chairperson
- 2. Professor Madhuri Behari, Member
- 3. Professor Vijay Kumar, Member
- 4. Professor Ramesh Juyal, Member
- 5. Professor Ravinder Gargesh, Member
- 6. Advocate Bulbul Das, Member
- 7. Advocate Omika Dubey, Member
- 8. Professor Amita Singh, Member
- 9. Professor Rajiv Bhat, Member
- 10. Professor Vaishna Narang, Member Secretary

The committee resolved to Approve - indicating that the proposal is approved as submitted; Approve – after clarifications – indicating that the proposal is approved if the clarifications Requested are provided to the satisfaction of designated committee members; [Approve after amendment/s – indicating that the proposal is approved subject to the incorporation of the specified amendments verified by designated committee] Defer – indicating that the proposal is not approved as submitted but it can be reassessed after revision to address the specified reason/s for deferment; Disapprove – indicating that the proposal is not approved for the reason specified.

Comments:

Member Secretary, IERB. Ethics Committee

Date of Approval: 19-11-2014

*(1st part to be filled in by PI and presented at the time of Review (Periodic, Continuing, Interim)).